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Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e80a>

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**THE ECONOMICS OF HEALTH-
CARE RATIONING: AN
EXAMINATION OF ALTERNATIVE
NORMATIVE CLAIMS**

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Thesis Submitted for the Degree of Doctor of Philosophy

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April 2002

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Submission date: 16 April 2002
Award date: 6 February 2003

THE ECONOMICS OF HEALTH-CARE RATIONING: AN EXAMINATION OF ALTERNATIVE NORMATIVE CLAIMS

Abstract

This thesis examines the economics of health-care rationing as an example of a real and substantive social choice problem. Throughout, it argues that existing approaches to the issue are not normatively appealing because the welfare-economics foundation on which they are based is exclusively consequentialist, that is, alternative states of affairs are assessed solely in terms of consequences. This is evident in health maximisation, one of the most commonly applied approaches to health-care rationing.

Arguments are presented that outline reasons why consequentialism may not be an appropriate philosophical basis for decision-making in health-care and the suitability of alternative non-consequential frameworks is examined. One particular approach to non-consequentialism, procedural preferences, is then developed in greater detail. It is argued that individuals have preferences for the methods by which decisions are made and that these preferences are derived from the inherent, as well as instrumental, value associated with alternative decision-making mechanisms. A taxonomy of procedural characteristics is developed.

Supporting empirical evidence for each of these sets of arguments is derived from two postal surveys of the UK general public. Triangulation is achieved through a media analysis of UK newspaper reports. The content of reports relevant to health-care

rationing were examined and coded in order to identify the frequency with which reference was made to alternative types of claims.

The thesis finds that the preferences of the UK general public in relation to rationing health-care are not adequately described by approaches such as health maximisation that have been commonly employed by economists. A pluralistic approach is advocated that integrates concerns from a variety of frameworks, both consequential and non-consequential in nature.

ACKNOWLEDGEMENTS

I would like to thank many people who have helped me to complete this thesis. My supervisor, Dr. Paul Anand has provided support and advice throughout this project. I have received generous financial support from the Trent Institute for Health Services Research, particularly Professor Mike Clarke, which allowed the survey work to be conducted. Likewise the Department of Economics, Open University provided financial support for the content analysis. Rachel Wailoo and Rachel Carmen acted as coders for the content analysis. This work has also benefited from the comments of my examiners, Dr Alastair Gray and Professor Maureen Mackintosh.

The arguments that form the basis of chapter three were initiated by Paul Anand and subsequently underwent several joint revisions together with the addition of the empirical work reported here. Participants at the Health Economics Study Group meeting, Birmingham 1999, also made several useful comments. This has been published in *Economica* (2000).

Chapter four was presented at the 2nd *International Health Economics Association* conference in York (2001) and has been submitted to *Health Economics*, Wailoo and Anand (submitted 2001). Work in a similar area is now being undertaken with Professor Paul Dolan, Dr. Aki Tsuchiya and Richard Edlin of the Sheffield Health Economics Group and the work presented here has benefited greatly from their comments. Funding from the *Arts and Humanities Research Board* (AHRB) has been awarded to develop this further.

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CHAPTER 2: AN OVERVIEW OF THE RATIONING DEBATE IN HEALTH ECONOMICS.

SUMMARY

The purpose of this chapter is to introduce the concept of economic evaluation in health-care. It reviews existing literature with particular reference to the debate that has been conducted between welfarists and extra-welfarists. The former approach focuses on utility as the maximand in social welfare whilst the latter group focus on alternative consequences, notably the Quality Adjusted Life Year. A second substantial body of work has recognised the importance of distributive equity considerations in health-care, particularly in publicly funded systems such as the UK NHS.

Numerous equity considerations are reviewed and represented graphically in terms of social welfare functions. These range from simplistic interpretations that focus on equal absolute health (or utility) or equal gains from health-care, to complex theories which span a range of equity considerations such as past health profiles, as in the “fair innings argument”, together with potential gains from health.

However, the review illustrates how the bulk of health economic research has considered issues of distributional, as opposed to procedural justice. The small amount of work that falls into the latter category in health-care is reviewed and related to theoretical work outwith the health economics field, notably the new welfare economic approaches which owe much to the work of Amartya Sen.

CHAPTER 3: QALYS, UTILITIES AND NON-CONSEQUENTIALISM: COMPETING CLAIMS IN HEALTH-CARE RATIONING.

SUMMARY

This chapter argues that QALY maximisation is not a sufficient basis on which to base health-care rationing decisions and that this is due to the consequentialist moral framework on which it is based. In this respect health maximisation parallels utilitarianism. An approach which draws on four alternative normative determinants of health-care entitlement is identified: rights, public opinion, social contracts and community values.

A survey was designed to test the extent to which these arguments were reflected in the views of a random sample of the general public. A number of conclusions can be drawn from the results. Firstly, our respondents systematically reject QALY maximisation. Secondly, reinterpreting benefit in a broader manner, for example to include those benefits, which might accrue to a patient's family, are similarly rejected. However, there is support for each of the alternative normative claims suggested. Results can be seen as lending support for pluralism in rationing guidelines, that is, a number of considerations, both consequential and non-consequential in nature need to be integrated.

CHAPTER 4: PROCEDURAL PREFERENCES IN HEALTH-CARE.

SUMMARY

The importance of procedures is an issue that welfare economists have traditionally ignored; procedures have been seen as relevant only to the extent that they facilitate better outcomes, that is, their value is solely instrumental. This chapter develops the findings from chapter three by focussing on this specific branch of non-consequentialist concerns. It challenges the instrumental view of procedures and suggests that, particularly in health-care, rational citizens hold what Rawls refers to as “pure procedural preferences”.

Drawing on contributions predominantly in the fields of social psychology and legal studies, a classification of procedural characteristics, which drive these preferences, is developed. A survey was then devised which tests the relevance of each procedural characteristic in three health-care rationing scenarios (decision making at the level of the individual doctor, health authority and government were tested). Results show that on average, each of the dimensions was considered important but that the extent of this differs according to the level of decision-making. Evidence also suggests that in some cases, aggregate preferences for procedures may outweigh those for consequences. Three distinct clusters of respondents were identified who might broadly be described as “anti-consequentialists” (38%), “proceduralists” (47%) and “pluralists” (16%).

CHAPTER 5: THE UK RATIONING DEBATE AND ECONOMIC FRAMEWORKS: A CONTENT ANALYSIS OF THE PRINTED MEDIA

SUMMARY

Utilitarianism, consequentialism and other frameworks have been discussed in detail in the context of health-care rationing in previous chapters. The arguments presented favour a pluralistic approach to health-care rationing. Survey evidence drawn from random samples of the public provided support for these arguments. This chapter outlines an alternative method of describing the way in which the UK health-care rationing debate is conducted and provides triangulation of previous chapter findings. Content analysis based on a selection of UK printed media was undertaken. Newspaper articles relevant to health-care rationing were analysed. The frequency with which arguments relevant to particular rationing frameworks occurred were classified accordingly. Results show that procedural issues dominate the way in which rationing issues are discussed in the UK media. There is strong evidence that voice, consistency and transparency are considered the most important dimensions of procedures. The results also indicate that a significant proportion of relevant articles discuss the relevance of efficiency in terms of health outcomes but that this criterion is not always supported as an acceptable basis for allocating treatments. Less evidence concerning the importance of rights, social contracts, non-health effects of health-care and the relevance of causes was identified. The promotion of a framework that combines both consequential and non-consequential information, suggested by previous chapters, is broadly supported by this content analysis although the implied importance of each component differs according to the evidence from media analysis.

CHAPTER 6: CONCLUSIONS

SUMMARY

Ultimately decision makers need to know how to assess competing claims for health-care resources. This chapter suggests alternative methods for operationalising the empirical evidence from previous chapters. A range of options are discussed. It is clear that further empirical work is required, if only to improve the sensitivity of the finding. Many economists favour a trade-off approach to integration which would entail, for example, the establishment of the trade-offs which individual are prepared to make between procedural issues and utilities or health gains in a similar fashion to the work that has been undertaken establishing efficiency/distributive equity trade-offs. However, it is argued that the methods which would allow such a task to be developed are not sufficiently well developed. Furthermore, the nature of the considerations identified in this thesis are not well suited to such thought experiments. Non-consequentialist concerns such as rights and procedures are often non-commensurable with concepts such as utility or health benefits. The alternative is to allow these issues to enter economic evaluations in much the same way as equity considerations do currently; as additional parameters to be considered by decision makers alongside cost-effectiveness ratios.

CHAPTER ONE: INTRODUCTION

1.1 HEALTH-CARE RATIONING: SOME BACKGROUND

The fundamental economic problem of scarcity is one to which health services are not immune. Since we could, in principle, spend many times the value of Gross National Product (GNP) on such services it is inevitable that they are rationed, whether by price or other means. Rationing is the term used throughout this thesis to refer to the practice of withholding potentially beneficial treatments from those that may be considered in “need” and is essentially an economic problem.

In political circles the term “rationing” has been conspicuously avoided^{1,2} by three strategies; dismissal of the scarcity problem, deflection of the issue by focussing on organisational inefficiency or funding levels, and substitution of the term “priority setting”. Priority setting may be more acceptable politically since it focuses on those who receive treatments rather than those who are denied treatments.

The UK National Health Service (NHS) has the following amongst its underlying principles, which no doubt contribute to the political unwillingness to acknowledge health-care rationing as an issue:

“The NHS will provide a universal service for all based on clinical need, not ability to pay. The NHS will provide a comprehensive range of services.” (Department of Health, 2001).

¹ See RCGP (2000)

² Klein (1998) notes that the then Health secretary Frank Dobson, had “banned the word from the ministerial vocabulary” (pp.959)

Yet these principles have remained largely unchanged since the inception of the NHS in 1948 but today at least three principle factors have forced rationing onto the political agenda. Firstly, technological change in health-care has occurred at a rate that far exceeds our ability to pay for it. Secondly, an ageing population has reduced the ratio of economically active persons relative to those who consume the greatest proportion of health-care resources; the elderly and the very young. Thirdly, the expectations of citizens have changed over the last fifty years. Some have argued that at the inception of the welfare state, services such as the NHS were viewed as privileges rather than undeniable rights as is the case today. The effects of rising incomes and consumerism have not been confined to goods provided in the market, see for example Coulter and Ham (2000).

Of course, the NHS has always rationed the services it provides. Indeed, within three years of its inception elements of price rationing were introduced. Prescription charges of one shilling (5p), which had been legislated for as early as 1949 but had not been implemented, were introduced in 1952. A flat rate of £1 for ordinary dental treatment was brought in at the same time³. However, the primary method by which the NHS rations services today is by waiting lists. At the time of writing over 1m persons are on an NHS waiting list in England and almost half of these have been waiting for over 3 months⁴. Furthermore, the NHS explicitly restricts the availability of certain interventions. In an analysis of health authority rationing behaviour, Redmayne (1995), Klein *et al.* (1996) identified a number of treatments that were explicitly excluded⁵. But much of this decision-making is made at a local level by managers and clinicians in an *ad-hoc* manner. This has been described a “rationing by muddling through”, Klein

³ Source: NHS (2002)

⁴ Source: Department of Health (2002) NHS Waiting lists, <http://www.doh.gov.uk>

⁵ Amongst the treatments specifically excluded were IVF treatment for certain age groups, sterilization reversal, varicose veins, certain types of cosmetic surgery, and gender reassignment.

(1998). Lengthening waiting lists and explicit rationing have elevated the profile of rationing as an issue in the National Health Service.

The problem of rationing is not restricted to the UK: many other countries with different health-care systems and methods of funding are grappling with the same problems, see Honigsbaum *et al* (1995), and an interesting development has been the increasing application of economic principles to the issue. However, economic evaluation is not an uncontroversial basis on which to ration health-care services as the experience in Oregon, USA exemplifies. The ‘Oregon experiment’ originated from the fact that the tax funded Medicaid budget, designed to provide medical services for the underinsured and uninsured, was not able to keep up with rising costs. The death of a young boy who had been waiting for a bone marrow transplant prompted a new approach to setting priorities explicitly in order to expand the numbers of people eligible for the Medicaid scheme. To address this problem a Health Services Commission was created and charged with producing ‘league tables’ of interventions. The intention was that these league tables would be based on cost-effectiveness and be used as a basis for explicitly rationing services. The Commission consisted of doctors, a nurse, a social worker and members of the public and they contacted interest groups, held public meetings and telephone surveys in attempting to achieve this ranking. The result of this extensive process was a series of league tables of condition/treatment pairs ranked in descending order of priority. In 1991 the first list of 700 conditions and treatments was produced but rejected by the legislature on the basis that it contradicted the rights of the disabled. Strong criticisms and headlines were provoked by the approach. It was condemned by politicians, patient groups and clinicians alike. After extensive revision the legislature provided funding for the top 565 out of 696 treatments. However, the influence of cost-

effectiveness as a driver of the list had become substantially diluted and subsequent changes abandoned the link altogether.

Nevertheless, the scheme need not be seen as a failure since its primary aim of widening health-care coverage within the state has been achieved, Ham (1998). Furthermore, Oregon was successful in getting physicians and politicians to acknowledge scarcity. However, the acceptability of economic evaluation (as currently formulated) in its largest practical application appears limited.

Economic evaluation is increasingly used in health-care rationing systems. For example, the creation of the National Institute for Clinical Excellence (NICE) in 1999 was specifically designed to provide guidance to clinicians on new drugs, treatments and devices in England and Wales, with economic evaluation as a substantial input. Australia was one of the first countries to require economic evaluation of new pharmaceuticals before agreeing to subsidise their cost in a national health scheme. Their Pharmaceutical Benefits Advisory Committee (PBAC) has been operational for over 7 years. In Ontario, Canada, pharmaceutical companies must prove that their products are cost-effective before they can be reimbursed by the government. Explicit rationing based on a mixture of social, economic and political criteria have also been implemented in Sweden, The Netherlands, New Zealand, and Norway, see World Health Organisation (2000).

This increasingly prominent role for economics within health services is not without controversy however and it therefore seems an appropriate time to reconsider “the economic approach”.

1.2 THESIS AIMS

This thesis views health-care rationing as an issue that economics should have much to contribute to, but questions the extent to which current formulations are useful. It examines the extent to which the general public systematically reject health maximisation, which underlies “cost-effectiveness”, or similar decision rules, as a basis for making health-care rationing decisions. It seeks to establish the extent to which such rejections are based on alternative normative claims, specifically those which are non-consequentialist in nature. The philosophical basis of welfare economics is wholly consequentialist in nature and, at least within economics, few alternative approaches have been developed. This thesis therefore provides both a novel critique of welfarism and provides empirical evidence in support of these claims from a real and substantive social choice problem.

Several original data sources are used as the basis for the investigation. Two postal surveys of the general public were undertaken and therefore provide unique datasets designed to test specific theoretical claims. A further analysis of media accounts of health-care rationing is included as an alternative and little used source of information.

There are both practical and theoretical implications. The findings of this investigation can inform the way in which health economic evaluations are currently constructed, or at least indicate the additional information that decision makers should consider. From the viewpoint of economic theory, health-care rationing can be seen as an example in which our understanding of social choice problems in general can be better understood.

1.3 OVERVIEW OF FOLLOWING CHAPTERS

Chapter two provides an overview of the health-care rationing debate in health economics. It outlines the practice of health economic evaluation and the concept of the Quality Adjusted Life Year (QALY). It then proceeds to review the primary contributions to our understanding of equity and its relevance to the rationing debate. Two broad issues are addressed by this chapter. Firstly, it outlines the main criticisms that have been levelled at QALY maximisation⁶. Whilst such criticisms are numerous they have concentrated on the distributional implications of decision rules. Secondly, it attempts to identify alternative normative claims that address these criticisms.

Chapter three builds on the existing evidence reviewed in chapter 2 in an attempt to better understand the reasons why members of the general public favour choices that systematically violate the decision rule of health maximisation. In an attempt to establish a normative framework for health-care rationing, a range of non-consequential issues are outlined and subjected to empirical examination using survey data.

Chapter four develops one particular branch of non-consequentialism, procedures, in the context of health care. It presents reasons why procedures may be of particular relevance in the context of health-care. A classification of procedural characteristics is then developed and a further postal survey used to obtain evidence so as to test the appropriateness of this class of concerns.

Chapter five provides triangulation by testing the relevance of frameworks suggested in previous chapters with an alternative data source; the UK printed media. The use of this type of data is rare in economics but can be found more frequently in the sociological

⁶ I shall use the terms QALY maximisation and health maximisation interchangeably.

and social psychological literature. The data generated provide an insight into the issues that underlie how the health-care debate is presented to the general public and are used to test whether the normative frameworks identified in chapters three and four are supported by evidence from an alternative source.

Chapter six summarises the main findings of the thesis. It makes several recommendations about how the findings of the thesis can be applied by health-care decision makers. It also outlines several stages of further research, some of which are already being undertaken, that are required in order for health economists to fully integrate issues of non-consequentialism into evaluations of health-care interventions.

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CHAPTER TWO:

AN OVERVIEW OF THE RATIONING DEBATE IN HEALTH ECONOMICS.

2.1 INTRODUCTION

The primary aim of this literature review is to outline developments in health economics applied to the issue of health-care rationing. It takes as its starting point the literature on economic evaluation, section 2.2, outlining the different types of analysis commonly employed. A crucial contribution of health economics is the concept of the Quality Adjusted Life Year (QALY) which is outlined in section 2.2.1. Section 2.3. describes the key elements of the debate between welfarism and extra-welfarism that has manifested itself in the health economic literature. Primarily this debate concerns itself with the nature of the outcomes that are appropriate for use in rationing decisions. Section 2.4 discusses a number of different approaches that have been taken to the issue of equity in health-care. These span simple uni-dimensional concepts of equity such as that based solely on health gain, to more complex accounts that combine different accounts of equity. The bulk of the existing literature is concerned with distributive issues. Section 2.5 examines the small amount of literature that is relevant to an alternative set of non-consequential concerns. Section 2.6 summarises the findings of this section.

The scope of this literature review is relatively wide and it would not have been feasible to include all relevant work in each of the separate areas. For example, Williams and Cookson (2000) report that over 1,000 works on “equity” and “health” exist within the Social Science literature from the past twenty years¹. However, the aim is to give the

¹ A review of this subject and empirical investigation of the use of equity information in health economic evaluations was recently published by Sassi *et al.* (2001).

reader an overview of debates and key contributions to each of the areas above while providing an up-to-date grounding for the contributions of subsequent chapters.

2.2 ECONOMIC EVALUATION IN HEALTH-CARE

Increasingly, health-care systems the world over are recognising the fundamental economic problems of scarcity and opportunity cost and have turned to health economists to contribute to the decision-making process. In organisations such as the National Institute for Clinical Excellence (NICE) in the UK², health economic evaluation comprises a key component of recommendations made to the health service regarding health-care technologies.

Three main typologies of economic evaluation can be identified which differ primarily in terms of the unit of measure used to quantify outcomes of competing technologies. These are cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-benefit analysis (CBA). Each of these evaluation approaches aim to assess the costs and benefits of competing health-care interventions and thereby promote the ‘rational’ or ‘efficient’ deployment of health-care resources, Gold *et al.* (1996).

In decision-making terms, cost-effectiveness ratios (CER) or cost-utility ratios (CURs), incremental costs divided by incremental benefits, are used to compare alternatives. An intervention that is both less costly and more effective is said to dominate the alternative. Where an intervention is more effective and more costly a decision must be made on the basis of the extent of the extra cost relative to the extra benefits.

² NICE was established as a special health authority in England and Wales on 1st April 1999.

In CEA, outcomes are measured and reported in 'natural' units relevant to the technologies in question. For example, alternative screening strategies might report costs per true positive case detected. Programmes designed to reduce smoking might be reported in terms of costs per life or life year saved. The approach is therefore, one which addresses issues of technical efficiency. The usefulness of CEA is restricted to comparing interventions which are expressed in the same units of benefit.

CUA is a specific type of CEA, although several, particularly US authors, do not make a distinction. It allows issues of allocative efficiency (within a fixed health-care budget) to be addressed, in addition to those issues of technical efficiency and is therefore considered by many to be a preferable form of analysis. The unit of outcome is the QALY (the details of which are presented below) which combines concerns for both quality of life and length of life into a single measure. The main contribution of this approach is that it allows seemingly diverse health-care technologies to be evaluated in a common currency. Cost-utility ratios are calculated as incremental costs divided by incremental QALYs generated and, since the benefits of all interventions are reducible (in theory) to QALYs comparisons can be made across seemingly diverse technologies.

The CBA approach expresses all relevant factors, both costs and benefits, in monetary units. It addresses both technical and allocative efficiency questions, that is, does the sum of the costs outweigh the sum of the benefits? Its theoretical basis is the potential Pareto improvement criterion which extends the Pareto principle to make judgements that entail both gainers and losers. However, few such studies have been undertaken in the health sector, primarily because the valuation techniques used, such as willingness-to-pay for health benefits or a human capital approach, are neither well developed at this time nor sufficiently appealing to decision makers. These methods have been used more

extensively in areas such as transport, energy and environmental economics. Of course, this final approach does have the additional advantage that decisions become more explicit; alternative approaches require decision-makers to decide whether additional benefits are worth the extra costs whereas CBA embodies such valuations as part of the analysis.

2.2.1 THE QUALITY ADJUSTED LIFE YEAR (QALY)

According to Drummond *et al.* (1997), the concept of the QALY can be traced back to Klarman *et al.* (1968) who, in evaluating competing interventions for patients suffering from kidney failure felt that existing measures of outcome were deficient in identifying the extent of differences between patients receiving hospital haemodialysis and those receiving a successful transplant. Whilst length of life was considered an important factor a measure which also considered quality of life was required to adequately reflect the difference between the two conditions³.

The QALY is a measure which reflects both of these dimensions of health benefit. It combines concerns for both quality of life and length of life. Williams's (1985) seminal paper on the economics of coronary artery bypass grafting was one of the first to calculate QALYs, albeit crudely, and highlight the strength of the approach in comparing treatments. The QALY weighs each year of life according to its quality using the anchor points of full health and death as one and zero respectively. Therefore, all health states receive a weighting relative to these points. For most health states a QALY value between zero and unity will be appropriate although there is no limiting floor applied, that is, severe health states may be valued as worse than death and therefore

³ A successful kidney transplant places virtually no restrictions on a persons physical abilities whereas haemodialysis requires a patient to be connected to a dialysis machine for several sessions per week each lasting several hours and strict limitations placed on exercise and diet.

receive negative QALY scores. These weightings are based on preferences and measured on an interval scale.

Several methods have been proposed for eliciting the appropriate values (or utility weights)⁴. Sometimes seen as the gold-standard, the standard gamble (SG) involves asking individuals to identify the extent to which they are prepared to trade health with risk of death and is based on the von Neumann and Morgenstern (1944) axioms of expected utility theory. For the valuation of health states which are preferred to death, two options are presented to an individual whose utility weights are sought, as shown in Figure 2.1 below. Option A consists of two possibilities; full health with probability p for the next t years and the inverse probability $(1-p)$ attached to immediate death. The alternative, Option B comprises the certainty of health state i , which is the subject of the valuation, for the next t years. The value of p is varied until the individual is indifferent between options A and B. At this point, the utility weight of health state i is equal to the value of p .⁵

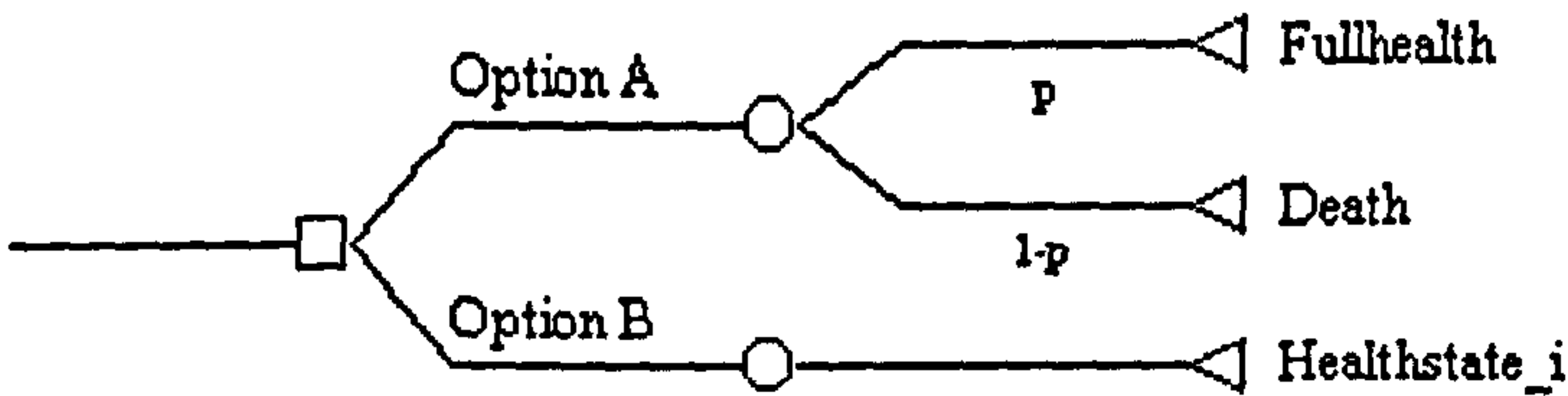


Figure 2.1: Standard Gamble for Chronic Health States

For health states considered worse than death the options need to be presented in a slightly different manner in order for indifference to be achieved, see Figure 2.2 below. Option A again consists of two possibilities; full health with probability p for the next t years and the inverse probability $(1-p)$ of health state i for the next t years. Option B is

⁴ Dolan (2000) provides a recent review of relevant issues.
⁵ Where indifference is achieved $p.1 + (1-p).0 = u(i) \Rightarrow u(i) = p$

immediate death. At the point where indifference is achieved the value of health state $i = -p/(1-p)$ ⁶.

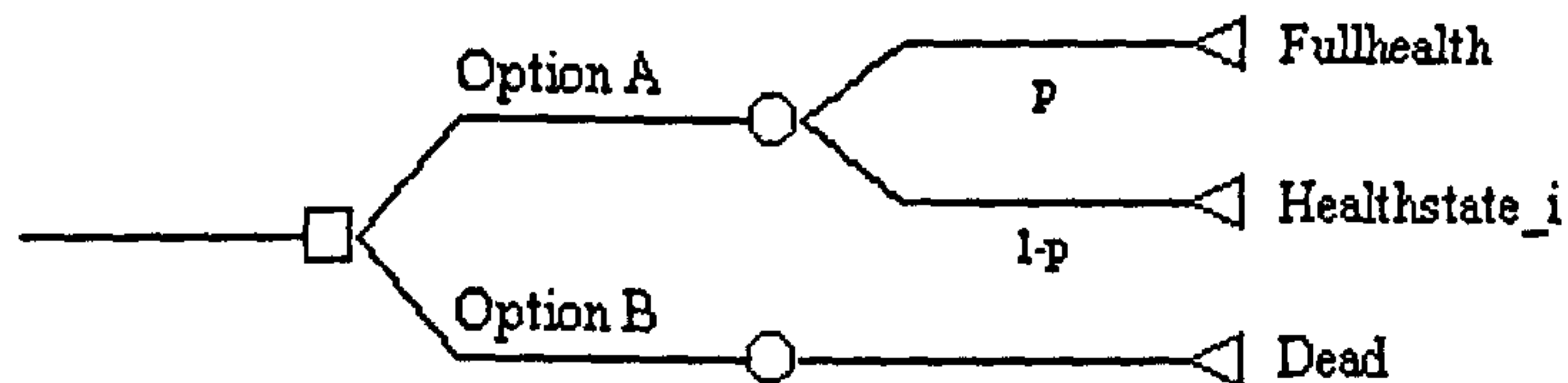


Figure 2.2: Standard Gamble for chronic states worse than death.

However, in practice respondents struggle with correctly interpreting probabilities, despite the use of visual aids such as chance boards or probability wheels, and find the exercise unnatural. Some believe that the validity of the SG approach is compromised by this difficulty, see Gold *et al.* (1996) and therefore alternative techniques have been advocated.

The time trade-off (TTO) is one such alternative, Torrance (1986). Here, values are elicited in scenarios which ask respondents to trade-off length of life with quality of life. For a chronic condition considered preferable to death, two scenarios are presented which the respondent must choose between, see Figure 2.3. In Alternative 1, the rest of the person's life (time t) will be lived in the intermediate health state i . In Alternative 2, full health will be enjoyed for a shorter time period x , followed by death. At the point of indifference $i = x/t$ ⁷. As with SG a variant exists for health states considered less favourable than death.

⁶ Where indifference is achieved $p \cdot 1 + (1-p) \cdot u(i) = 0 \Rightarrow u(i) = -p/1-p$

⁷ Where indifference is achieved $u(i) \cdot t = x \Rightarrow u(i) = x/t$

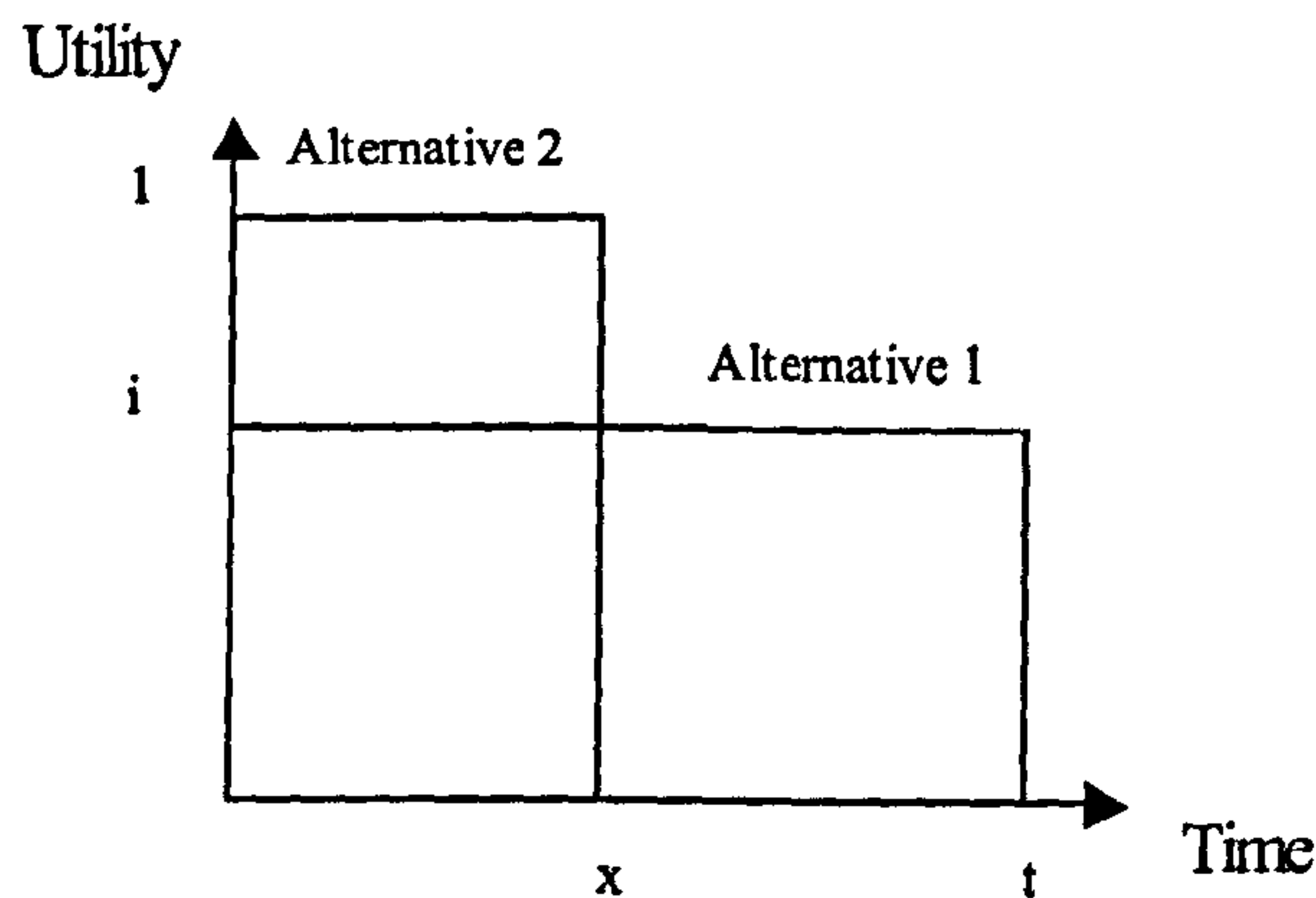


Figure 2.3: Time Trade-off Chronic states

A third class of preference elicitation techniques have been derived from psychometric tools. The primary advantage of tools such as Visual Analogue Scales (VAS) is that they do not entail the same cognitive burden for respondents as either SG or TTO. The VAS technique entails asking respondents to indicate on a scale, which may be marked from 0-100 for example, where they would rank health states such that the intervals between their placements correspond to their perceived preferences. Some studies have used the anchor points “best imaginable health state” and “worst imaginable health state”, for example MVH Study Group (1995). Whilst this class of techniques are the most simple to administer it has been argued that a number of measurement biases exist, see for example Brazier *et al.* (1999), and the scores generated are not an interval scale of preferences, although Torrance *et al.* (1996) has suggested a means of transforming such scores to equivalent SG or TTO values, as have Dolan and Sutton (1998).

An important clarification is included at this point. Whilst the use of QALYs in economic evaluation is referred to as cost-utility analysis, and that the basic tenets of utility theory are used to derive the values which are used in determining QALY weights, the QALY is not a measure of utility in the welfarist sense, Wagstaff (1991).

Utility theory is used to measure health but it is not possible for individuals to receive different QALY values for the same health state, although they may well generate different utilities.

Furthermore, the QALY is not the only measure which claims to be a preference based measure of health. The most notable alternative, the Healthy Year Equivalent (HYE) was developed as a response to the claim that QALYS do not accurately reflect individual preferences, Mehrez and Gafni (1989). The details of this claim are presented in Appendix 2.1. However, since most commentators have concluded that the HYE is in fact theoretically equivalent to the TTO method the issue is not considered further, see for example Buckingham (1993), Culyer and Wagstaff (1993). Perhaps the greatest contribution of the HYE however, irrespective of the strength of its claims to accurately reflect individual preferences, is that it encourages thought to be given to the concept of health profiles rather than discrete states that are additively separable. It is well documented that preferences for health states are sensitive to ordering and sequence effects, for example Krabbe and Bonsel (1998), and the HYE does therefore reflect an important theoretical point for measuring health preferences, although the practical usefulness of such an observation has been questioned⁸.

2.3 WELFARISM AND EXTRA WELFARISM

Whilst the theoretical basis in relation to preferences of the QALY as a measure of health has been questioned, the focus of this thesis is on the use of the QALY in health-care rationing decision rules. An existing distinction relevant to this issue which features strongly in the health economics literature is that which exists between welfarists and extra-welfarists.

⁸ For example, a relatively simple Markov model with 8 health states and 20 cycles would require 8²⁰ HYE assessments, in excess of 10¹⁵, Kielhorn and Graf von der Schulenburg (2000).

It is often claimed that the cost-benefit approach to economic evaluation, which attempts to value the outcome of health-care interventions in terms of patients' willingness to pay (WTP), is derived directly from welfare economic theory and that this is the correct basis for economic judgements to be made, Birch and Donaldson (2000). Welfarism asserts that social welfare is a function of individual utilities and that those utilities are derived from the consumption of commodities by those individuals. Birch and Gafni (1995) argue that neither CEA nor CUA are compatible with the principles of welfare economics and that the alternative ethical basis they embody cannot be justified. Particularly, they point out that normative judgements must be made in deciding whether the benefits identified in the course of such evaluations (whether measured in 'natural units' or QALYs) are worthy of the additional costs and have argued elsewhere, Gafni and Birch (1994), that such an approach is likely to lead to continuing increases in health-care expenditures. For QALYs to be accepted by welfarists as the appropriate outcome measure they must be viewed as utilities, an assertion which is generally viewed as inappropriate, Brouwer and Koopmanschap (2000). Therefore, CBA is the approach more generally favoured by welfarists.

One area in which the potential shortcomings of the QALY approach has received considerable attention is in field of "process utility". Since the QALY approach reflects individual utilities only to the extent that they are reflected in differences in health status, it is not capable of incorporating individuals preferences for the process of care⁹. See for example Ryan *et al.* (1998), Donaldson and Shackley (1997).

⁹ Although it is claimed by some proponents of the WTP approach that inclusion of such "process utilities" is a non-consequentialist approach (see for example Birch and Donaldson, 2000. p.10) the definition of consequentialism used throughout this thesis does not support such a claim. For example, whilst an individual may get utility from gourmet catering in hospital and be prepared to trade this off for utility or health, this is an outcome. It is not a health outcome and it is derived from the process of

Extra-welfarism is a normative alternative to welfarism, where the maximand is not restricted to utility and “may embrace whatever maximand may be given by the customers of research or inferred by diligent enquiry by the analyst to be relevant” Culyer (1988). Non-welfarism in health therefore, refers to a broad categorisation of those who “admit non-utility information about individuals into the process of comparing social states” (Culyer, 1991, p.89), amongst them those who advocate the maximisation of “health”.

The approach owes much to the work of Amartya Sen (1979, 1980, 1982a, 1982b) whose critiques of the foundations of welfare economics have highlighted its limitations and urged the explicit consideration of issues such as “liberty, discrimination, exploitation, or entitlement to social security.” (Sen, 1979, p.554). That is, it emphasises the importance of non-utility information. In his theory of capability rights, Sen (1987) the Rawlsian notion of primary goods, Rawls (1971), rather than utilities is extended. Sen argues that the focus of attention should be on the distribution of basic capabilities; for example the capability to move about without harm, Sen (1982b), which focuses attention towards what goods do for people rather than goods themselves. The view is therefore one which transcends rather than excludes individual welfares from the analysis.

To focus on health, as the QALY approach does, can be normatively justified on this non-welfarist basis. Culyer (1989, 1990) argues that the QALY approach represents a departure from welfarism since it is concerned with the characteristics of people (i.e. their health) rather than the utility generated as a result of those characteristics. Health is

medical care but this remains consequentialist. “Process utility” is not coterminous with “procedure” in a philosophical sense. “Non-health enhancing utility” would be a more suitable term.

thus the primary outcome of interest under this framework with the QALY seen more as a representation of a health achievement capability than a utility.

It is worth noting here that extra-welfarism retains a consequentialist limitation; that is, it is concerned with outcomes rather than processes, Hurley (1998), despite the fact that much of Sen's writing is concerned with non-consequential considerations. This is discussed in subsequent sections but the important point to note here is that welfarism is based only loosely on Sen's work.

2.4 DISTRIBUTIVE CONSIDERATIONS AND EFFICIENCY TRADE-OFFS

The welfarist / extra-welfarist debate revolves around the specification of an appropriate maximand. Whilst any single outcome can then be used in a simple maximising framework, for example QALY maximisation or utility maximisation, health economists have examined a number of alternative methods of explicitly integrating equity considerations into decision-making frameworks. Equity considerations are defining characteristics that distinguish health and health-care from most other commodities. Indeed this is one of the guiding principles of the UK NHS. Of course, even simple maximising approaches embody some notion of equity even if this only arises by default. QALY maximisation for example, considers every QALY equal, no matter why, to whom and at what stage of life it accrues. In this sense it can be claimed that the approach is "fair", see Williams (1974), Wagstaff (1990), which may be true but it is only one form of equity.

One way in which alternative equity considerations have been conceptualised is as a trade-off with efficiency, where the maximisation of QALYs is seen as the efficient

solution¹⁰. In Wagstaff (1991), this concept has been represented diagrammatically in terms of a health production possibility frontier and a similar approach has also been followed in a review of equity issues in health by Williams and Cookson (2000). The approach has also been taken in Dolan (1998), Dolan *et al.* (2000) and Dolan and Olsen (2001). For clarity, this representation is also used here to illustrate some of the primary contributions to the study of equity in health. This approach aims to identify the social welfare function based on societal preferences for alternative distributions of the maximand with the aim that the social welfare function itself then becomes the objective function. However, many economists have argued that economic efficiency and distributive equity considerations should be kept quite separate and that economists should only engage in analysis of the former, for example Kaldor (1939) quoted in Sassi *et al* (2001).

Figure 2.4 shows the classic health maximisation viewpoint. The axes of the diagram may be thought of as the health, measured in terms of QALYs, of A and B where A and B are either two individuals or groups of individuals. FF represents the health possibility frontier which identifies the boundary of those combinations of health, measured in QALYs, which are technically feasible. In this example, QALY maximisation is described by linear welfare contours 45° to the origin. There is no concept of equity here, except that which emerges by default; that a QALY is a QALY wherever and however it is generated. If social welfare is best represented by maximising the number of QALYs generated, then the optimal position is X in Figure 2.4.

¹⁰ It is not necessary for health maximisation to be the efficient solution.

At the other extreme is the position that would be taken by a pure health egalitarian, represented in Figure 2.5. In this situation, additional total health is valued only to the extent that it accrues to the least well off person; equivalent to the Rawlsian-type “maximin” principle, see Dolan *et al* (2000) or Williams (1997). Therefore, welfare contours are ‘L-shaped’ and kinked around a 45° line from the origin. Yet such a concept of equality is highly inflexible and many have sought to develop more accurate conceptions of equity applied to health.

Perhaps the most well documented of such claims is that relating to age. Since the ability of older individuals to generate QALYs is, *ceteris paribus*, less than the young, the QALY approach contains an inherent bias against the elderly when making comparisons between some interventions. For example, a life saving intervention might would appear less cost-effective in elderly groups compared to young groups¹¹. Harris (1987, 1988) for example, claims that since the elderly have less years to live the value of each additional year of life is higher for them than the young. Fairness in choosing between the young and old is achieved by applying equal value to the desire to continue to exist for Harris. Evans (1997) also argues that the ageist implications of QALY maximisation are not ethically justifiable. He argues that attaching different weights to individuals on the basis of life expectancy, as would be done when comparing life saving interventions, violates the fundamental principle of treating everyone equally. Furthermore, he objects to the value of life being assessed by reference to its length. Such criticisms point to a need to adopt the patients perspective since they are the ones best placed to value their own lives.

¹¹ Since a larger proportion of health care needs occur in elderly groups it is not necessarily the case that QALY maximisation would result in an “ageist” outcome when assessing an entire health care system. I thank Alastair Gray for this point.

However, in a review of empirical evidence little support was found for weighting QALYs in favour of the elderly, Dolan and Shaw (2001). Bowling (1996), Bussbach *et al* (1993), Cropper *et al* (1994), Johannesson and Johansson (1997), Lewis and Charny (1989), Mooney *et al* (1995), Nord *et al.* (1996), Rodriguez and Pinto (2000), and Williams (1998) all cite evidence that health gains to the young are weighted more highly than those to the old.

Indeed, Williams (1997a) argues that the potentially ageist implications of QALY maximisation may be justified in equity terms, as opposed to efficiency terms, by reference to what he calls the "fair innings argument", which he attributes to Harris (1985)¹². In fact, this argument can be used to support the weighting of QALYs generated by the young more heavily than those generated by the elderly. In simple terms this states that everyone is entitled to some 'normal' span of life years; those failing to achieve this may reasonably feel "cheated" whilst those achieving more than this are "living on borrowed time."¹³ One strength of the argument is that it is based on consideration of an individual's lifetime experience rather than the situation they are currently in. An additional contribution made by Williams is the integration of quality of life with concerns for an individual's length of life. A "fair innings" cannot be said to have applied to an eighty year old that has lived each of those years in pain or suffering from disability. In the example he uses to devise equity weights, differences in quality adjusted life expectancy at birth between social classes are estimated as measures of inequality and, although the data used are acknowledged to have some problems, the general "fair innings" principle is one which is supported by some survey data.

¹² Harris (1988) states that "I am not, however, ultimately attracted to such a principle [the fair-innings] and I believe, for the same reasons, that whilst it has some claims to fairness it has also features which involve profound injustice and that these are stronger." P.93.

¹³ Alternative formulations of the fair-innings are discussed in Tsuchiya (2000).

In Williams (1997b) the argument in favour of age-based rationing is suggested on the basis that there are reasonable limits to what can be expected from the health service for elderly people (and everybody else). The priority that younger individuals enjoy as a result of QALY maximisation is derived from the fact that health benefits are valued using the same metric. To behave otherwise requires the sacrifice of large benefits for young people to provide small benefits for the elderly, and Williams can see no reason why these small benefits should be valued more highly. He refutes two arguments that are often used to support the entitlements of the elderly in health-care. Firstly, Williams argues that whilst the elderly may have paid taxes all their lives to finance health-care the government “did not promise to provide everything possible no matter what the costs.” For Williams, the NHS represents a social insurance scheme rather than a saving’s club and it is not therefore appropriate to advocate entitlements to services which were not in existence when these contributions were started¹⁴. A secondary argument for valuing years of life saved in elderly groups higher than years saved in younger groups is that this is how the valuations from the individuals concerned would run; the elderly value their small improvements more highly than the young value their large improvements. Williams’ objection to this argument is that it rests on individual rather than societal values and is therefore inappropriate in the context of a social insurance system.

In a similar view, the World Bank (1993) promulgates the use of age weights which further bias against the elderly in addition to that generated by health efficiency arguments. Their report advocates applying age-weights which are in excess of unity between the ages of about 10 - 50 years, and weights below unity in childhood and elderly years. These scores, which are intended to be relevant to the countries in which

¹⁴ This point is discussed in more detail in subsequent chapters.

the World Bank deals (primarily low income countries), reflect the social value of individuals at different ages. The middle years are the most productive in terms of productive activity such as child-rearing and work. This concept was further refined in Murray (1994) as the Disability Adjusted Life Year (DALY) which attempts to measure the burden of disease. Disability valuations are achieved using a two-stage PTO process. The overall DALY value is calculated by multiplying the disability value by the number of years lived in that health state and is added to the number of years lost due to the disease. The results are then discounted and age weighted to achieve a DALY value¹⁵, although the procedure has been criticised on the basis of the value judgements it entails, Anand and Hanson (1997), Arnesen and Nord (1999).

Of course, the concept of the fair innings as an equity concept can conflict with QALY maximisation although in many cases it supports it. In situations where an older person generates larger QALY gains than a younger person the fair-innings principle may still advocate that we treat the younger. Tsuchiya (1999, 2000) identifies this implication and discusses in more detail those theories which support ageism on equity grounds.

Such approaches can be represented in terms of health by changing the slope of the social welfare contours to indicate a greater weight to one group relative to the other as in Figure 2.6. Here group B may be thought of as an elderly group relative to the young members of group A where there is a lower social value attached to health gains for the elderly, although age is one of a number of possible reasons for applying such weights.

The idea of weighing QALYs on the basis of lifestyle characteristics such as the cause of illness or whether the individual suffers from a pre-existing disability has been

¹⁵ The DALY is therefore a "bad" that should be minimised.

discussed elsewhere. The former case embodies a notion of equality that relates to opportunity rather than distributions of health, LeGrand (1982, 1991). In this situation, each individual should be provided with an equal opportunity to achieve health but they retain the ability to choose how they exercise that opportunity. Compensation must be made to those who suffer through no fault of their own but no such obligation exists to compensate those whose problems are adjudged to be self-inflicted.

The latter case has been the subject of a series of papers debating the 'double jeopardy' argument, Harris (1987), Singer *et al.* (1995). Here it is argued that the QALY maximising approach is flawed since it entails allocating lower priority to those already in lower health states because interventions cannot restore them to as high a quality of life as those without such pre-existing conditions. They are therefore twice penalised: once by being unfortunate enough to have the pre-existing condition and secondly by being overlooked for current treatment as a result of being inefficient QALY generators.

Furthermore, Harris (1987) argues that the fundamental problem with the QALY approach in this respect is that it entails a valuation of life equivalent to the value of the health status index in which a person finds themselves¹⁶. Nord (1992) highlights the fact that the QALY approach values a life in a wheelchair as of less value, in addition to being less healthy, as a life without disability, a position which:

"is ethically highly controversial and disabled people find it repugnant. In an egalitarian society like Norway their reaction is shared by most of the general public. Similar egalitarian values probably prevail in other European countries." Nord (1992. P.875).

¹⁶ Note that, in practice, economic evaluation would rarely entail a valuation of life as in this example.

In response to this Nord suggests the use of an alternative measure of social value to the QALY; the Saved young life equivalent (SAVE). Based on the hypothesis that the saving of a young life person and restoring that person to full health may be seen as the maximum possible benefit that a single individual can obtain. Alternative interventions are then expressed in terms of the number of SAVES from responses made by the population. Nord argues that this approach is a much more direct method of expressing social value and is therefore easier for members of the public to understand. He also envisages that the use of such figures, in cost per SAVE ratios for example, should not be as prescriptive as the use of QALYs.

Another interesting contribution to the concept of social valuation of alternative health interventions developed by Nord (1995,1999) is the Person Trade-Off (PTO). This technique attempts to elicit values by asking respondent how many persons would have to receive a certain health gain in order to be equal to a given number of persons receiving a different health gain. A series of such questions can be asked in order to derive a scale of undesirability between conditions, Torrance (1986), although the technique is little used.

Nord (1995) also argues on equity grounds that differences in the no treatment profiles might be an important equity consideration; that is priority should be given to those whose prospects are worse should they not receive the treatment. Olsen (1997) provides empirical support from Norway for this concern with those with poor health prospects.

This, and other theories such as the fair innings approach, are developed further in Dolan and Olsen (2001). They suggest that not only are lifetime quality adjusted healthy

years a relevant concept, as in the "fair innings argument", but that it is important to identify the extent to which previous health-care interventions have contributed to that stream versus the number of QALYs otherwise obtained "free". They argue that the concept is reflected already in entitlements to other welfare services (for example, unemployment benefits are determined in part by the amount of benefit previously received) and that the moral basis for such an approach can be defended in several ways. The first mirrors the defence of the "fair innings" argument; that equity should be based on a lifetime view rather than equity from a particular point in time onwards. Secondly, equity considerations may be motivated in part by consideration of "just desserts" and this can operate at different levels; if previous need for health-care was due to engaging in risky behaviour then entitlements for current health-care may be justifiably lower even if current need is due to "bad luck". Alternatively, it may be considered reasonable to reduce entitlements where both previous and current health-care needs are the result of a person's choices, and that this should reduce entitlements even if those choices may be unrelated, for example lung cancer through smoking and liver damage through drinking. Of course an even weaker acceptance of the just desserts argument is that entitlements should be affected only if both previous and current health-care needs are due to the same own choice, for example recurrent lung cancer from continual smoking. Using a health related social welfare function as in figure 2.7, the potential conflict between four equity considerations are shown together with the potential trade-offs each entails with efficiency (health maximisation).

The diagram shows a starting point "e". The associated health feasibility set, $h_A h_B$, shows the boundary of possible health gains for individuals (or groups of individuals) a and b. PG_a and PG_b indicate the amount of prospective gain for the two individuals. The point at which health gain is maximised is given by the point of tangency between the

health frontier and a line sloping from left to right at a 45° angle¹⁷. This point is labelled H_{\max} . Equality of prospective gain is represented by a 45° ray emanating from the origin of the prospective gain space and is labelled E_{PG} . In this example, equality of prospective gain and prospective gain maximisation are not equal since A and B do not have an equal capacity to benefit from treatment. Arrow 1 therefore represents the classic equity-efficiency trade-off as discussed by Wagstaff (1991). To highlight the importance of consequences without health intervention the feasibility set is located within prospective health space, represented by the axes PH_A and PH_B . In this example, A is assumed to be in a worse condition than B. The ray E_{PH} represents equity of prospective health and the relevant trade-off between health maximisation and this principle is given by arrow 2. Note that in this situation, these two alternative equity principles actually pull in different directions since the person that gains most from treatment is also in the most severe health state.

To illustrate considerations of equal lifetime health both the feasibility set and the prospective health space are both located within the total health, TH , space. In this example, it is assumed that person B has experienced less health than A, for example because s/he is younger. Equal lifetime health is represented by E_{TH} . Arrow 3 shows the trade-off between health maximisation and equity in lifetime health.

The addition made to the equity-efficiency trade-off literature by Dolan and Olsen is represented by arrow 4; the trade-off between health maximisation and equity in total health gain. In this example, part of B's health is attributable to previous health-care use. Therefore, the equal total health gain line is given by E_{TG} .

¹⁷ This is similar to the welfare contours outlined in Figure 2.4.

2.5 BEYOND CONSEQUENCES

The issues reviewed above represent the primary contributions of health economics to the health-care rationing issue. However, a common characteristic of both welfarist and extra-welfarist approaches and alternative approaches to incorporating equity considerations, is that of consequentialism. Consequentialism can be seen as a common component of both utilitarianism, on which the cost-benefit approach claims it is founded, and QALY maximisation. It is a moral philosophy which evaluates competing states of affairs solely by reference to the consequences each generates and has been criticised on the basis that it cannot deal adequately with acts undertaken for reasons such as duty or commitment, which are undertaken independently of the expected consequences, Minkler (1999). Moral motivations are only captured to the extent that they promote particular consequences. Non-consequentialism does not abandon all reference to consequences; competing health-care rationing schemes cannot be assessed without reference to the utilities or health gains they produce, but allows a broader set of considerations to enter the analysis as Daniel (1994) suggests:

“What [non-consequentialists] deny is that a rule’s having the best overall consequences is *constitutive* of its correctness...they simply hold that it is not a *necessary* truth that normatively correct decision procedures will have the best overall consequences”. (pp.13 quoted in Minkler).

In terms of the health production possibility frontier, issues of non-consequentialism have been represented as ethical constraints on the opportunity set by health economists; which may rule out some or all of the “efficient” options¹⁸. Williams and Cookson

¹⁸ It is possible that procedures which are instrumentally valuable, i.e. they promote better outcomes, would not have the effect of reducing the feasibility set. Furthermore, it is possible that certain sections of the feasibility set are ruled out rather than the simplistic shrinking characterised in Figure 2.8.

(2000) represent such an approach by shrinking the feasible set as in Figure 2.8. In this situation the feasible set is effectively reduced from FF to F^1F^1 . This viewpoint corresponds to what Sen refers to as “constraint-based deontology” in his discussion of rights, Sen (1982b). However, this is a rather extreme alternative to consequentialism since it entails allocating an importance to non-consequential information that entirely transcends those concerns for consequences, that is, they lexicographically dominate. Utility or health maximisation can only take place in a sphere which is decided on by reference to non-consequential issues. The viewpoint may be applicable to certain types of rights; violating certain rights may be seen as simply wrong irrespective of the utilities generated. Non-consequentialists need not commit to a view as extreme as the constraint based approach. Furthermore, many other types of non-consequentialist information exist in addition to rights.

An alternative representation that embodies non-consequentialist concerns, and allows the realization and failure of rights *inter alia* to play a part in determining the social ordering is suggested by Sen and referred to as a capability rights system. This is a framework which permits a variety of social issues, such as well-being and poverty, liberty and freedom, development, gender bias and inequalities, justice and social ethics to be analysed, Sen (1993). It is therefore an approach which is based on a much richer informational basis than alternative approaches which Sen considers normatively inadequate and is the only approach currently discussed by economists that emphasis the importance of both consequential and non-consequential considerations.

In the capabilities framework commodities are of importance because of their characteristics. The characteristics of commodities enable *functionings*: for example, a bicycle assists with the ability to move about freely. The relationship between

commodities and functionings is determined by both an individual's characteristics, for example genetic history, and social characteristics, for example institutions or public policies. Sen supplements the concept of functionings with the concept of *capability*, which refers to the set of functionings that a person could have achieved. Achieved functionings are not sufficient for determining well-being in the capability approach but must be combined with the notions of opportunity and choice in evaluating welfare.

For Sen, the practical implications of this have been to encourage a movement away from the narrow economic focus on statistics such as Gross Domestic Product (GDP) per head as a measure of well-being and look instead at levels of literacy and women's rights, particularly in low income countries. Indeed a series of reports in this area represent the greatest impact of the capability approach on policy making, UNDP (1990-1999).

However, it should be noted that these approaches have been largely descriptive, Robeyns (2000). For example, Sen's own attempt at illustrating the capability approach in the context of living standards in developing countries, Sen (1985), showed that measures of life expectancy, infant mortality, basic education and tertiary education, often contradicted measures of GNP per capita and that therefore differences in public policy *inter alia*, had huge impacts on capabilities such as survival and education. Similarly, the series of indices generated by the United Nations Human Development Reports are relatively crude in their synthesising of functionings.

Whilst the non-welfarist literature owes much to Sen's welfare economic approach it has almost exclusively remained within a consequentialist paradigm. For example, whilst Dolan and Olsen (2001) recognise parallels between their work and that of Rawls

(1971) they stress that their work is concerned solely with outcomes rather than rights or procedures to primary goods.

More recently, Sen (2001) himself, discusses the relevance of the capability approach to health and health-care. In this address he argues that assessments of health equity must go beyond distributive considerations to include rights, capabilities and procedures. The latter are promoted on the basis that procedural fairness is a crucial component of welfare, that is, as part of the set of social conversion factors that influence the relationship between an individual's ability to transform commodities into functionings.

Verkerk *et al.* (2001) have also reviewed the capability approach as a means to developing more appropriate measures of health-related quality of life and similarly pointed out the relevance of “the broader socio-political environment can be a source of value”.(pp.53) although they are wary of the additional information required in operationalising the approach. For example, the need to identify the appropriate functionings.

An outline of how the capability approach might operate in the context of health care comes from Anand (1999) who used non-linear programming methods. QALY maximisation may be formalised thus:

$$\text{Max} \sum Q$$

with a single budget constraint:

$$b \leq B$$

where Q is the number of QALYs generated, b the actual total cost of treatment and B is the budget for health-care.

Anand's approach suggests that non-consequential considerations might enter either as additional constraints or as part of the maximand. For example, the maximand may be reformulated as:

$$\text{Max} \sum_g w_g Q$$

where $w_g=0$ if a person is considered responsible¹⁹ for their own condition and 1 otherwise.

A constraint in addition to the budget might take the form of:

$$n(g) = k \forall g$$

where g refers to the group considered for treatment. This reflects equal numbers of people from different groups need to be treated and could be applied, for example, to groups of individuals of different ages.

Another notable contributor to non-consequentialist discussion in the context of health-care comes from the philosopher Norman Daniels. A recurrent theme throughout his writing on this subject is the claim that consensus on distributive principles is absent and legitimacy of rationing frameworks can only therefore be established by reference to procedures, see for example Daniels and Sabin (1997), Daniels (2001), a view which is credited to Rawls' (1971) theory of justice. The concept of fair procedure is referred to as "accountability for reasonableness". Clearly if the principles of distributive justice could be agreed and were sufficient in themselves to determine social justice then the legitimacy of health-care rationing could be assessed quite easily, or at least the problem would be one of information. Yet it is clear that no such consensus exists as the proceeding sections underline. Given such distributive disagreements, "we must retreat to a process all can agree is a fair way to resolve disputes about them." (Daniels, 2001.) Goold (1996) invokes the same rationale as Daniels for seeking acceptable procedural

¹⁹ For example, if we wish to exclude smokers from health-care entitlements.

methods in health-care. Daniels develops this approach by suggesting the procedural components of a decision-making mechanism which would satisfy the need for legitimacy and this is the subject of subsequent chapters in this thesis. However, it is interesting to note at this point that one of the key components of fair process for Daniels is public participation in decision-making.

Another contribution to the health-care literature comes from Mooney (1998) who develops a theory of “communitarian claims” based on Broome’s (1989,1991) original claim concept. The proposition is that individuals cannot be viewed independently of the communities in which they live²⁰ and that activity within that community is inherently, as well as instrumentally, valuable. This leads to the recognition that the community has duties to meet claims but that it is the community that decides which are appropriate. Under this approach issues such as the relevance of self-induced illnesses, weights to health gains according to age, which undermine health maximisation as a legitimate goal can be advocated although whether this constitutes a departure from consequentialism is unclear to Mooney who points out similarities both with utilitarianism and rights.

2.6 SUMMARY

This review summarises the main contributions economists have made to the problem of health-care rationing. It differentiates three economic evaluation typologies and clarifies how new approaches to welfare economics, particularly the extra-welfarist approach inspired by Amartya Sen, have been developed and applied to this area by health economists.

²⁰ This also supports the idea of eliciting community, as opposed to patient preferences regarding health-care.

A significant literature has developed in relation to alternative concepts of distributive justice but the review identifies the paucity of research that has examined the relevance of non-consequential considerations in health-care. Sen recognises that equity is a key characteristic of societal attitudes to health and health-care, and procedural justice is a key component of equity. It is apparent therefore, that there is scope for further development of Sen's new welfare economic approach to the health-care rationing issue and that that development ought to address issues of non-consequentialism. Sen's capability approach is the primary framework that has discussed such issues and limited empirical applications to areas such as human development have been undertaken using this framework. The relevance of this approach to health and health care has yet to be established however.

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Appendix 2.1: The Healthy Year Equivalent (HYE)

By definition the QALY model is a bivariate utility function with the arguments length of life and health.

The value of a chronic health state can be given by:

$$U(Q,T)=V(Q).T$$

Where $V(Q)$ is the value of health status Q and T the duration of the state

A health profile that changes over time is given by:

$$U(Q_T)=t \sum V_i(q_i)$$

Where t is the time interval of the period and $V_i(q_i)$ the utility associated with each period. The QALY model of individual preferences is therefore based on a number of assumptions, *inter alia*:

- Mutual utility independence between life years and health status: The utility of a health state is independent of the number of years that health state will endure and the utility of the number of years is independent of the health state.
- Constant proportional trade-off between life years and health status: The proportion of life years an individual is willing to sacrifice for a health improvement is independent of the absolute number of years of remaining life
- Additive utility independence between time periods: Total QALYs = $t_1U(Q_1)+...+t_nU(Q_n)$

However, three sets of criticisms have been levelled at the QALY model. Firstly, individuals do have a positive time preference for health rather than the zero rate assumed by the QALY model, see for example Cairns and van der Pol (2000). Secondly, the duration of a health state influences the value that is placed on that health state, perhaps because of coping effects, see for example Sackett and Torrance (1982).

Thirdly, the sequence in which health states occur throughout a health profile also influences the valuations given to that profile see for example, Krabbe and Bonsel (1998), Richardson *et al.* (1996), Lowenstein and Prelec (1993). The Healthy Year Equivalent (HYE) is an attempt to overcome these problems. HYE's differ in two respects to QALYs. Firstly, they measure preferences over an entire profile of health states rather than individual health states that make up the profile. Secondly, a two-stage standard gamble procedure is used.

In Stage 1, as shown in Figure A.1, the probability p is varied until the individual is indifferent between full health with the probability p and the health profile. In Stage 2, shown in Figure A.2, the number of years in full health (Hyears) is varied until equivalence with full health with probability p^* is established.

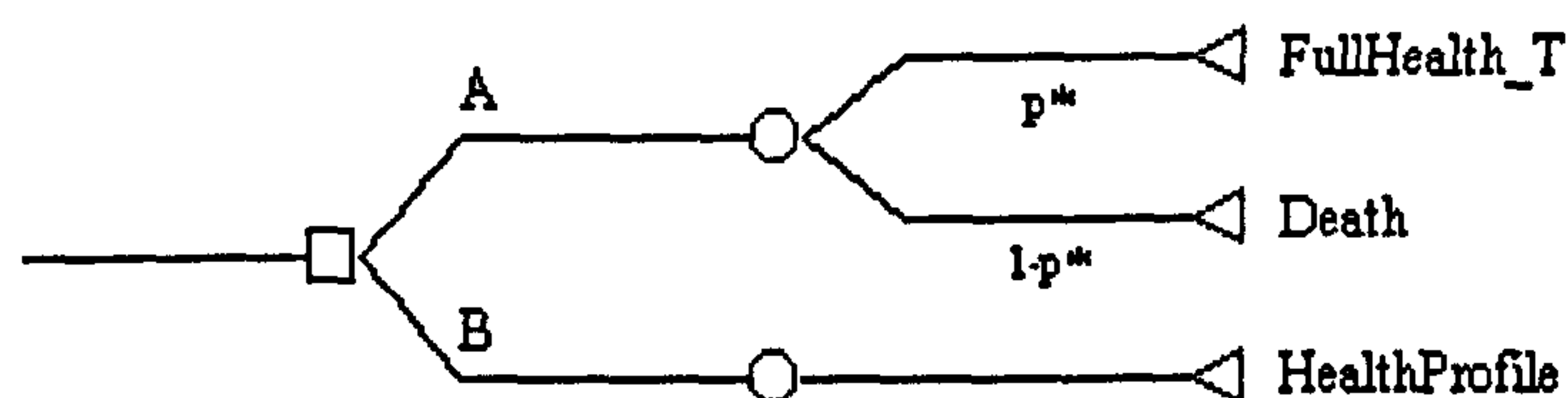


Figure A.1

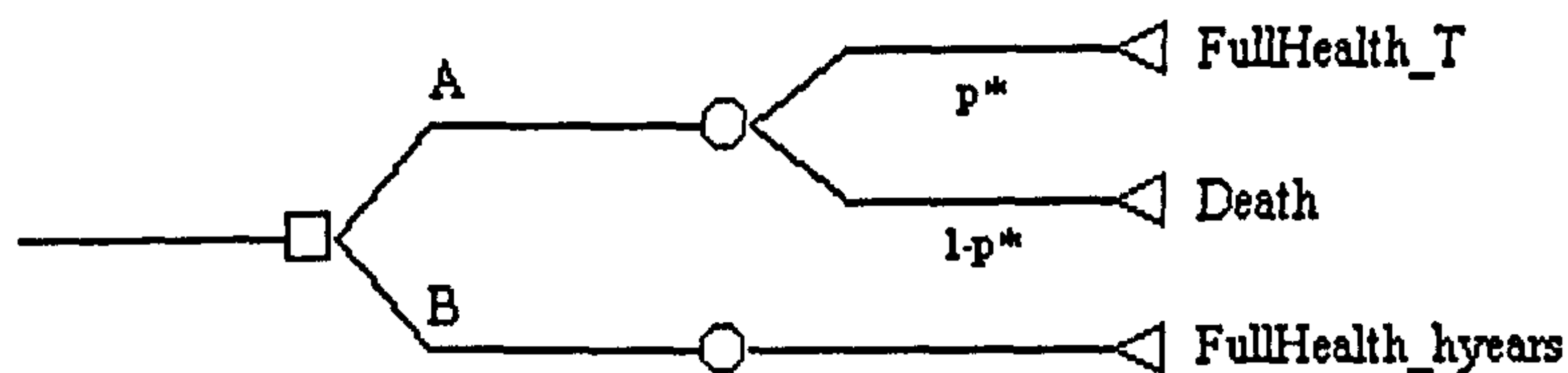
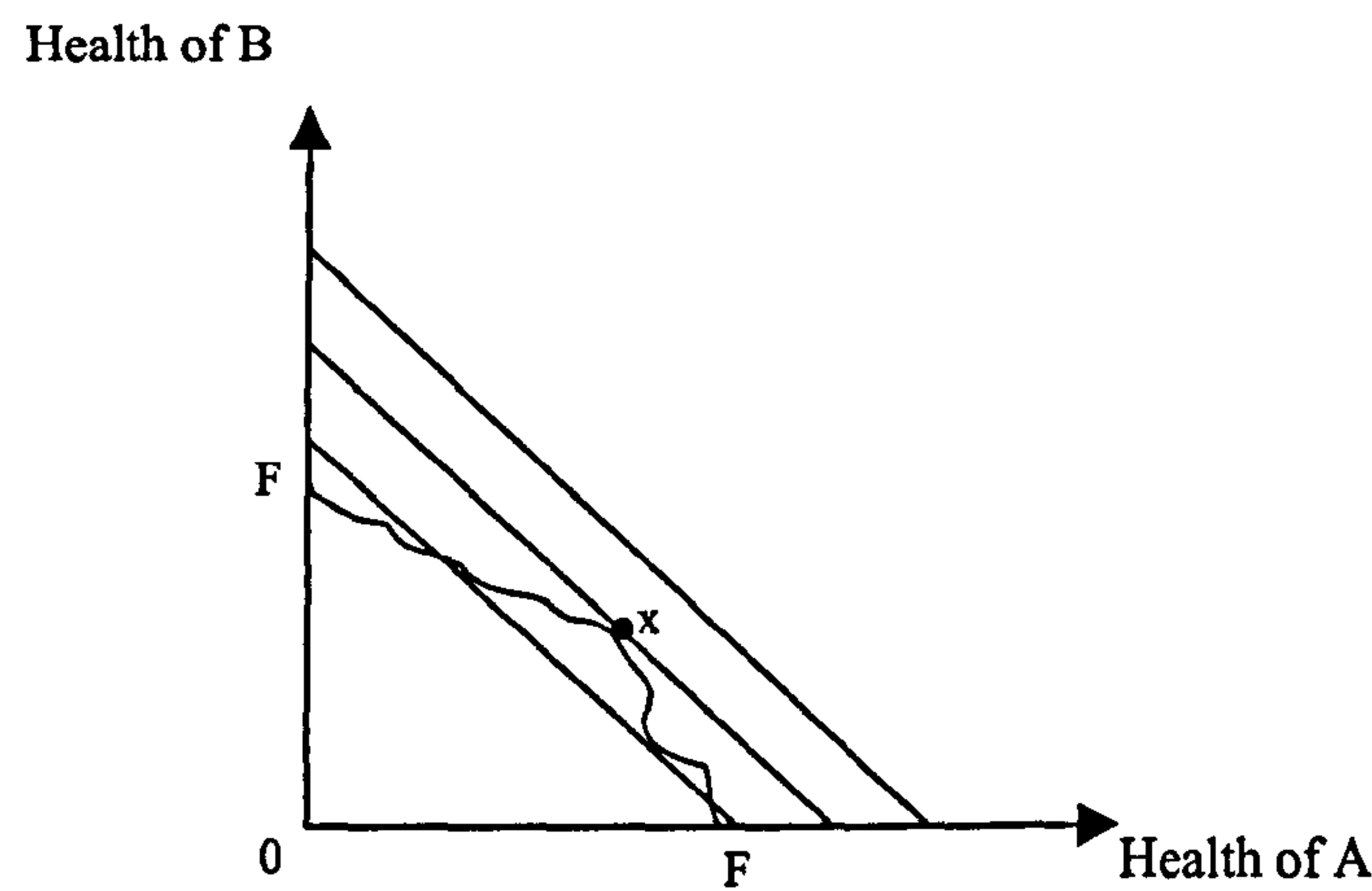


Figure A.2

Critics have argued that this approach is in fact equivalent to the simpler, one-stage time-trade off, see for example Culyer and Wagstaff (1993), Buckingham (1993).

Figure 2.4: Health Maximisation



Adapted from Williams and Cookson (2000)

Figure 2.5: Pure Egalitarianism

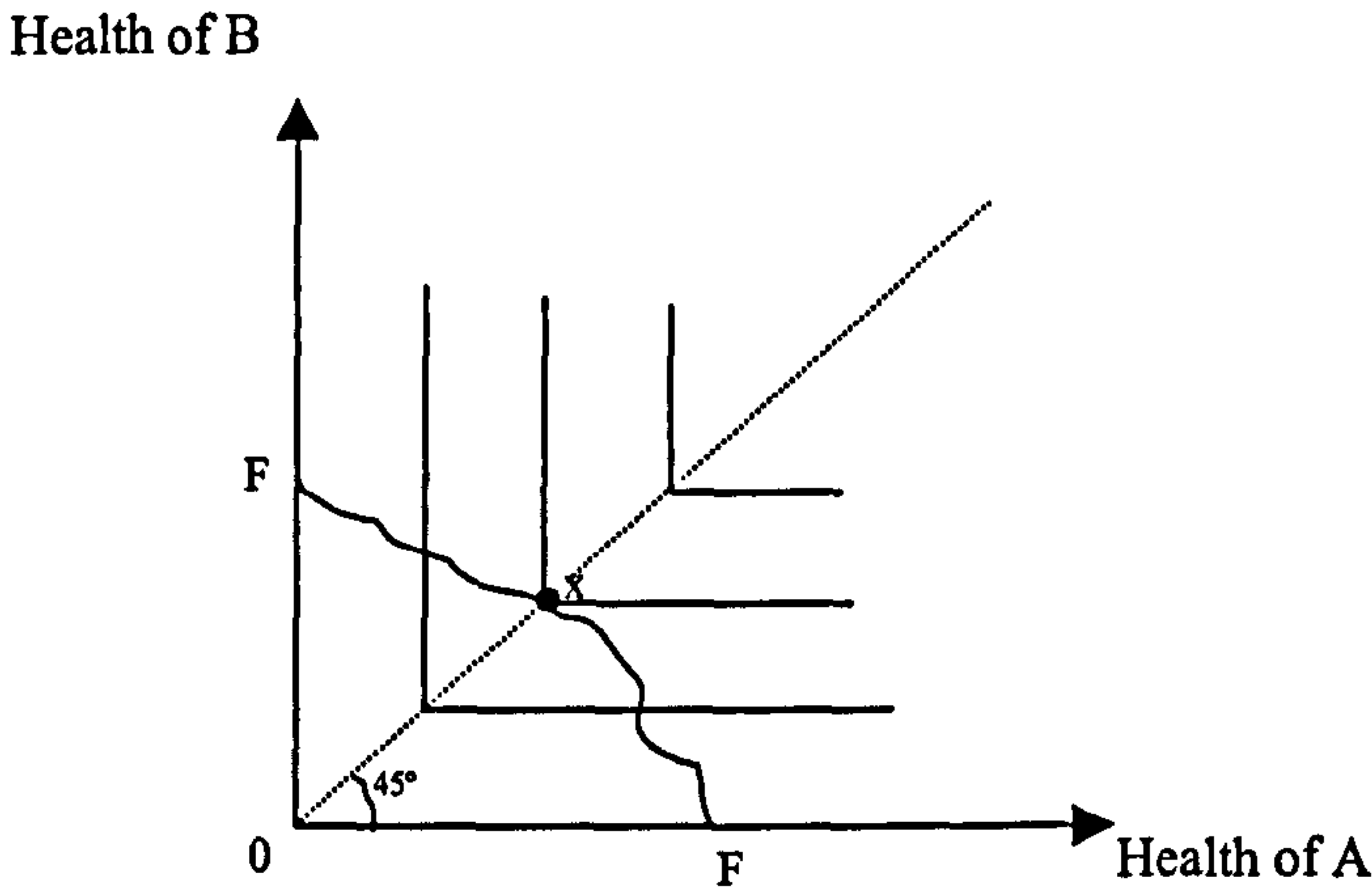


Figure 2.6: Equity weighting of health benefits

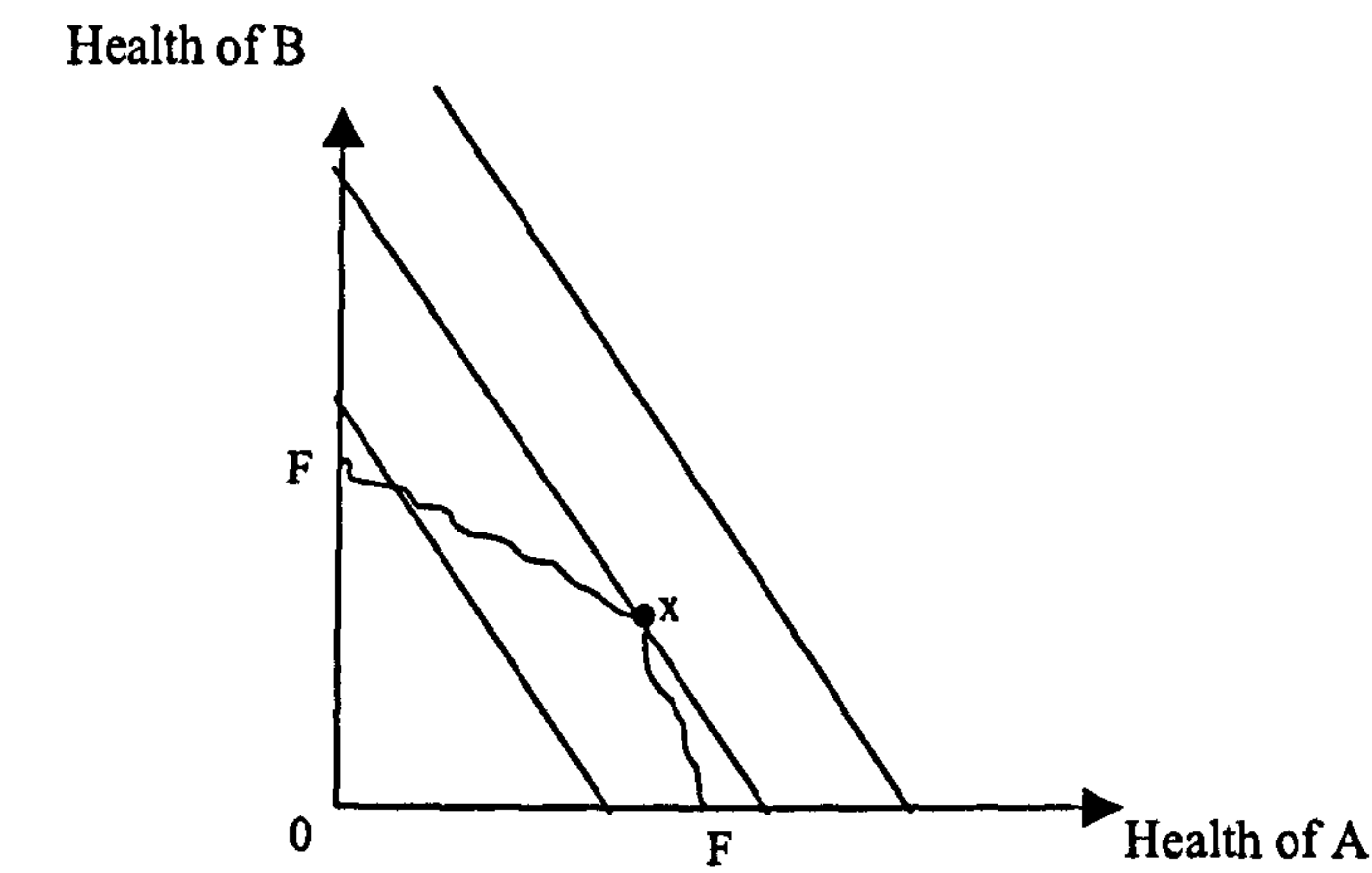


Figure 2.7: The importance of different health streams (from Dolan and Olsen, 2001)

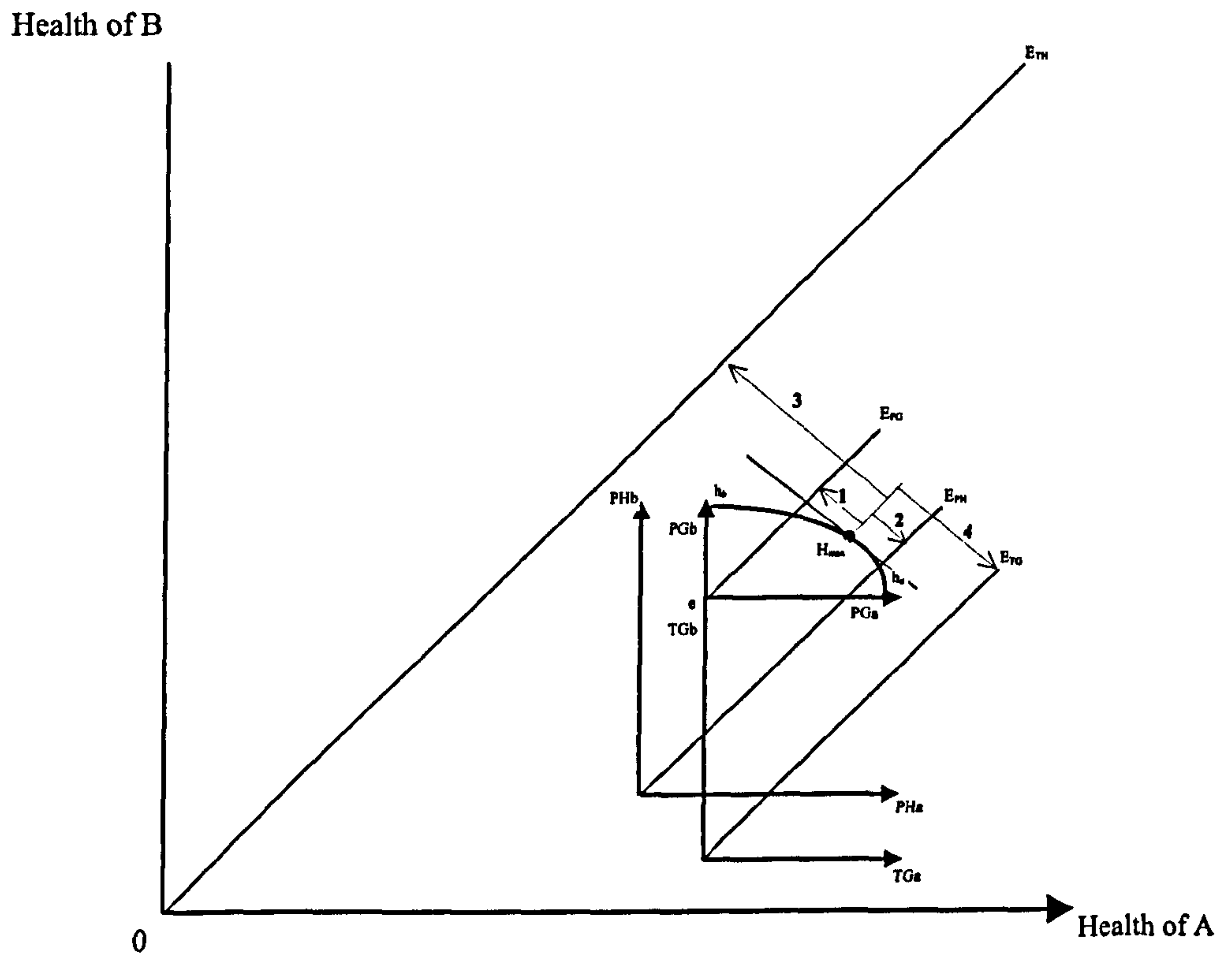
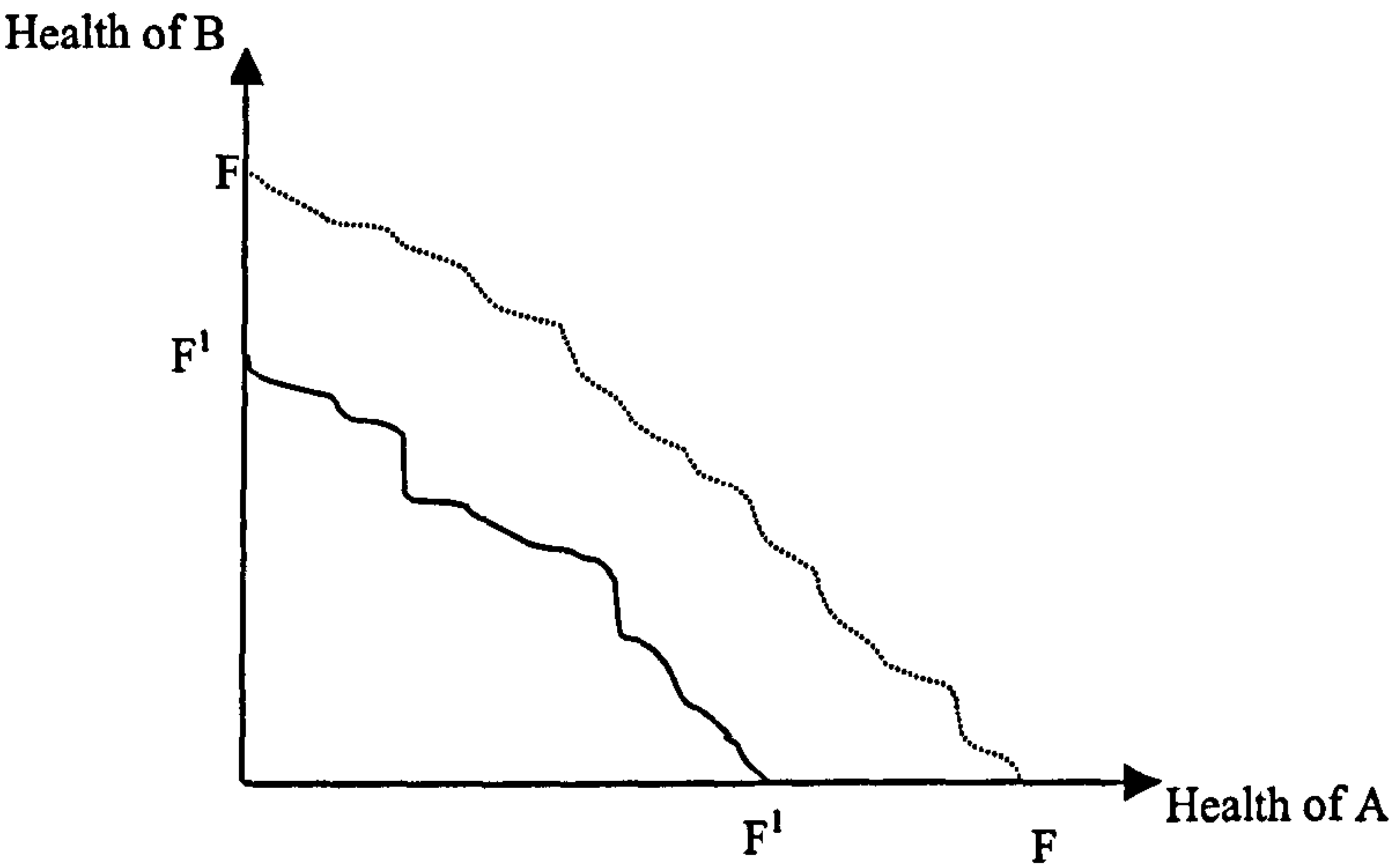


Figure 2.8: Constraints on the Feasibility Set.



CHAPTER THREE: QALYS, UTILITIES AND NON- CONSEQUENTIALISM: COMPETING CLAIMS IN HEALTH- CARE RATIONING.

3.1 INTRODUCTION

One of the most conspicuous contributions of health economists to the rationing debate is the concept of the QALY. Recognising the fact that the majority of health interventions have implications for both length and quality of life, health economists have been involved in the elicitation of preferences to establish the relative weights that should be given to each of these dimensions. As a result, it is claimed that the QALY is a utility based measure of health outcome which anchors all health states around death (zero) and full health (1). Undoubtedly, the fundamental insight on which QALYs are based (that the outcomes of health interventions in terms of both quality and quantity of life are important) is correct and as a measure of the strengths of these preferences may be acceptable¹. However, the concern of this chapter is not with the accuracy of the QALY as a *measure* but the decision *rule* of QALY maximisation as a means of establishing health-care priorities.

Such a task is not new; numerous critiques have been made of QALY maximisation. However, the criticisms presented here are derived from a different normative basis. This chapter is based on non-consequentialist critiques of QALY maximisation. Furthermore, despite existing critiques QALY maximisation retains substantial appeal

¹ For present purposes the QALY is assumed synonymous with preferences for different health states that is, QALYs accurately measure what they claim. See Chapter 2 for a discussion of this issue. However, the argument about the use of QALY maximisation as a decision rule is prior to these arguments about the

amongst those who see the approach as a natural extension of welfare economic theory.

As Williams (1996) states, the logical decision rule associated with QALYs is to maximise their total number since this is compatible with some economic interpretations of efficiency. A similar kind of view can be found in Broome (1988) who claims that QALYs are aimed at providing an assessment of the “total of good”, the natural extension of which is that one would wish to maximise their number subject to some budget constraint.

The following section clarifies some terminology and contrasts the non-consequential approach with existing methods adopted in the health-care rationing literature. Section 3.3 details three sets of criticisms of the QALY maximising approach which would apply to any consequentialist social choice rule. In section 3.4 a number of alternative claim types are outlined. Subsequent sections, 3.5. and 3.6., outline the methods and results from a postal questionnaire which tested hypotheses related to issues discussed in 3.3. and 3.4. Section 3.7 concludes.

3.2 THE RELEVANCE OF NON-CONSEQUENTIALISM²

Traditional welfare economic theory is utilitarian in nature: both “old”, Pigovian, welfare economics which relied on interpersonal comparisons of utility, and “new” approaches based on the Pareto criteria, Suzumura (2000). The informational basis for assessing social welfare that is utilitarianism consists of three key characteristics identified by Sen and Williams (1982); Welfarism; sum-ranking; and consequentialism. QALY maximisation is derived from traditional welfare economic theory in that it maintains the properties of sum-ranking and consequentialism. However, since QALYs

use of the QALY as a measure. If basic philosophical objections to the use of “health gain” as a rationing tool exist then there is little point in pursuing a more accurate measure.

² For more details of the literature discussed in this section please refer to Chapter 2.

and utilities are not coterminous, see for example Wagstaff (1991), Birch and Gafni (1992), the QALY approach has been criticised on the grounds that it is not founded on economic theory. Cost-benefit analysis (CBA), using willingness-to-pay (WTP), conjoint analysis (CA) or a human capital approach, has been advocated by some health economists as a superior alternative on the grounds that it is capable, at least in theory, of incorporating wider concerns (utilities) than simply those for health gain (QALYs), see for example Donaldson and Shackley (1997), Ryan and Shackley (1995), although even this claim is not without controversy, see Tsuchiya (1999). However, utilitarianism as a theoretical foundation is increasingly being dispensed with by moral philosophers, Korsgaard (1993) and Scheffler (1988), and economic and social choice theorists, Sen (1979, 1985a) and Kolm (1994, 1995). Indeed in many cases, utilitarianism and QALY maximisation fall together since they share the common characteristic of consequentialism.

Consequentialism evaluates states of affairs solely in terms of outcomes and therefore has nothing to say about the multiplicity of rights and other competing claims which dominate the way in which medics, health ethicists and the public think about health-care rationing problems. Furthermore, this may not be particular to health, as work on social choice theory by Sen (1979) argues. Whilst an understanding of non-consequentialist objections to QALY maximisation contributes to our understanding of the health-care rationing problem, where non-consequentialist concerns may be more conspicuous, it is also the intention that this work appeals to social choice theorists for whom issues of non-consequentialism lie at the heart of current research, see for example Suzumura (1999).

The following arguments against QALY maximisation advocate a non-consequentialist alternative but this does not necessitate a rejection of measures of outcomes entirely; consequences may be important (and QALYs *may* be more appropriate than utilities) but not exclusively so. The contention here is that a defensible (normatively desirable) rationing system will be pluralistic, that is, it must incorporate concerns for outcomes with a number of alternative claims.

3.3 ARGUMENTS AGAINST QALY MAXIMISATION

The intention of this section is not to present a comprehensive account of the basis for rejections of health maximisation but to detail those which may exist as reactions to the consequentialist foundation of the approach. Three sets of objections to QALY maximisation are presented in this respect.

The first concerns a generalised rationing problem in which the incorporation of QALY differences into the decision rule leads to allocations that entail potentially arbitrary exclusions from treatment. Objection number two deals with questions of causation that are excluded from all consequentialist approaches. Sometimes such exclusions are of debatable significance but it will be shown that there are strong, normatively compelling reasons why some elements of QALY differences should be eliminated from the determination of entitlements. The third objection provides counter-arguments against a significant body of work that has attempted to support QALY maximisation using the “veil of ignorance” concept suggested by Rawls (1971).

In several examples anti-consequentialism and “anti-maximisation” are not mutually exclusive. There is overlap between some of the objections raised here and those that

have been discussed in existing literature. The crucial contribution here though is the focus on anti-consequentialism.

3.3.1 Arbitrary Exclusions From Treatment

Any rationing decision inevitably excludes individuals from treatment and, when focussed at a macro level, such as the problem faced by health authorities or those responsible for national guidelines such as the National Institute for Clinical Excellence (NICE), exclusions of groups of individuals results.

The contention here is that exclusions based on QALY maximisation appear arbitrary. Furthermore, replacing “QALYs” for different measures of outcome is equally unacceptable. It is consequentialism rather than QALYs *per se* which are wrong.

The following simplified scenario, based on one of the most well-documented implications of QALY maximisation, illustrates. Suppose society is divided into two mutually exclusive groups X and Y. A disease affects members of both groups, is fatal if not treated but victims are restored to full health and life expectancy (which is equal for both groups)³ if treated. In this situation life years equate to QALYs. The only difference between the groups is the age at which the disease strikes. Members of group X contract the disease with probability p_x ⁴ at age a_x . Corresponding facts hold for members of Y (see Table 3.1).

Treatment costs are assumed equal to one unit for everyone which must be funded from a health-care budget size B. The budget is sufficiently constrained that it would not be

³ “Life expectancy” is here used to refer to the fact that persons are expected to live to the same age rather than for an equal additional period.

⁴ This is the conditional probability of contracting the disease, given membership of X.

possible to treat all patients in either group, i.e. $B < \text{Min}(n_x p_x, n_y p_y)$. This simple but quite general account of the rationing problem helps us ask how the health-care budget should be spent.

QALY maximisation makes a clear prescription and gives treatment to all those in the group where the disease strikes first, since a greater number of (quality adjusted) life years are generated. Furthermore, this prescription is one which must hold even where the difference between onset ages $|a_x - a_y|$ is very small, perhaps only one year. Yet it is clear that such a prescription generates outcomes which may seem somewhat arbitrary. If, for example, groups X and Y consist of 40 and 41 year olds respectively then the decision to exclude those in the latter group on the basis of this one year difference in age appears unfair. Even many of the '40 year olds' might feel that a small age difference (hence a QALY difference) is not sufficient to entirely exclude one group from the opportunity of treatment, particularly in the extreme where treatment may be a matter of life and death. It is perfectly true that if a member of the 41 year old group struck had been a member of the 40 year old group, health maximisation would have preferred them so there is a sense in which health maximisation does provide equality of opportunity. However it is an equality that depends on the truth of a counterfactual which seems only artificially relevant. For many people, the fair solution is one that gives an equal opportunity of treatment to those who are in need. In this case, that means the set of affected individuals who are in either category. People with these intuitions do not accept that being one year older, and hence generate one extra QALY (less when discounted to present values), is enough to exclude a person from being considered for treatment.

Interestingly, most other consequentialist rationing methodologies suffer the same exclusion problem as QALY maximisation. In the case of utilitarianism, groups or individuals who differ only in terms of their abilities to generate utility provide little information relevant to the rationing decision. Dependant utilities, such as those derived by family, friends or society via productivity, provide a weak basis for excluding treatments from those who could benefit as individuals. Even a decision rule which assessed a restricted range of utilities, for example those accruing directly to potential patients only, would have to deal with several problematic issues. For example, should those considered more efficient producers of utility (the happier of the patients) be prioritised?

Similar exclusions are also entailed as alternatives to maximisation are explored. Effectively, irrespective of the notion of distributive equity used, exclusions from treatment will be made and if these are assessed solely by reference to some dimension of consequence will appear arbitrary. For many individuals, rationing health-care on the basis of *any* measure of outcome, and using *any* definition of distributive justice will be seen as unacceptable due to exclusions appearing arbitrary. QALY maximisation is simply one of many alternative specifications that are undermined on this basis. This is not to say that non-consequentialist approaches can avoid exclusions that might appear arbitrary but that this will be either more acceptable and/or appear less arbitrary when non-consequential information is also used in the assessment of 'goodness' or 'fairness'.

3.3.2 The Relevance of Cause

Health maximisation, as with all species of consequentialism, is blind to causes. It makes no difference either how or why a person generates QALYs, just that they do The

exclusion of issues of causation is the source of two types of failing in the QALY maximisation framework.

Many health-care rationing issues as presented in both media, political and popular discussion place great emphasis on the relevance of personal responsibility in determining entitlements to publicly provided health-care services and previous work by health economists has also found such preferences, see for example Ratcliffe (2000) for evidence of preferences for lower priorities for alcoholics requiring liver transplants. In France mountaineers are legally required to take out insurance to pay for rescue services and in the UK such services are often provided by volunteers and charitable contributions. Those who believe that the extent to which a person is responsible for their medical needs should influence their access to publicly funded health-care cannot be consequentialists and *a fortiori* cannot be advocates of health-care maximisation. If an individual believes the reasons for requiring treatment are important then they are not merely concerned with consequences and cannot be thought of as a consequentialist⁵.

Furthermore, the issue of cause relevance goes beyond the concept of personal responsibility. For example, there has been substantial debate about the source of potential QALY data. One such concern revolves around the representativeness of traditional clinical trials where patients are typically younger than real world patient groups, Baltussen *et al.* (1996). Correcting for such potential biases is necessary to establish an accurate outcome measure but there are many situations where entitlements should be established after factors causing QALY differences have been factored out rather than in. Particularly relevant here are those instances where groups may generate

⁵ This follows standard linguistic practice in philosophy. In economics there is sometimes an effort to show that everything can be fitted into a particular framework. Even where this is logically possible it is not necessarily helpful conceptually.

lower health gains due to socio-economic differences. Failure to factor lower abilities to generate health gains out of QALY measures penalises patients for their status by withholding treatments from them.

Treatments may have lower expected benefits for low income groups due to inability or unwillingness to accurately follow a course of treatment or adhere to a new set of behaviours. Lower economic status is positively correlated to scepticism about the usefulness of medical care, the possibility of lower valuation of life and therefore increased risk taking, and lower educational achievement. Examples of these effects in terms of their health outcomes are evident in numerous areas. Graham (1995) shows that smoking cessation programmes are less effective for young, working class mothers, relative to their middle class equivalents, due to limited recreational alternatives and higher exposure to stressful conditions. Compliance with treatments for diabetes, Garay-Sevilla *et al.* (1998), asthma, Apter *et al.* (1998) and even haemodialysis, Bame *et al.* (1993), where non-compliance has an almost immediate effect on health, is lower amongst the less well-off. Pure QALY maximisation must reflect these differential health outcomes by allocating lower health-care priorities to lower income groups even though such differences should perhaps be ignored.

QALY maximisation further discriminates against low income groups since life expectancy is positively correlated to wealth. If poor people suffer simply because the expected QALYs generated following successful treatment are less (the poor die younger), then there is no doubt that QALY differences should be ignored. The point mirrors Harris's (1987) 'double jeopardy' argument against the use of QALY maximisation in assessing the benefits accruing to a disabled person:

“QALYs dictate that because an individual is unfortunate, because she has once become a victim of disaster, we are required to visit upon her a second and perhaps graver misfortune.” (Harris, 1987:pp.120)

The practical response to this is straightforward. Where life expectancies differ for reasons we wish to factor out, assume a standard life expectancy for all groups or treatments. The difference may be subtle but it is no longer QALY maximisation⁶ and it differs for reasons outwith consequentialism.

3.3.3 Rational Egoism and the Veil of Ignorance.

QALY maximisation has been promoted as an ethical decision rule on the grounds that the resulting distribution of health-care resources mirrors that which would be chosen by a rational egoist from behind a veil of ignorance. This tool for assessing fairness was first suggested by John Rawls (1971) as an alternative to utilitarianism although it has since been subjected to criticism most prominently by Harsanyi (1976). To defend QALY maximisation on these grounds however, constitutes a powerful defence given the attention the veil of ignorance has received in philosophy, economics and medical ethics as a method of assessing justice in social settings. Choices made from behind the veil are deemed “fair” in both procedural and distributive terms.

Singer *et al.* (1995) discuss several examples in their defence of QALY maximisation, a paper which arose as a response to Harris (1987). The discussion here focuses on just

⁶ Standardised life expectancies are often used in evaluations, for example, population based life table estimates of life expectancy applied to treatments for less well-off patients whose actual life expectancies may not correspond.

one of these which is defended purely on the grounds of the health benefits accruing to the two persons involved⁷.

Imagine two persons are both affected by a heart condition which will rapidly prove fatal if left untreated. Treatment costs for both are equivalent. Each has been involved in an accident which has caused permanent injury (one is in a wheelchair whilst the other has a limp) corresponding to QALY scores of 0.5 and 0.95 respectively. Life expectancies are also equivalent. How would the rational egoist choose to allocate one treatment from behind the veil of ignorance? For clarity the options are presented in the form of a decision-tree in Figure 3.1.

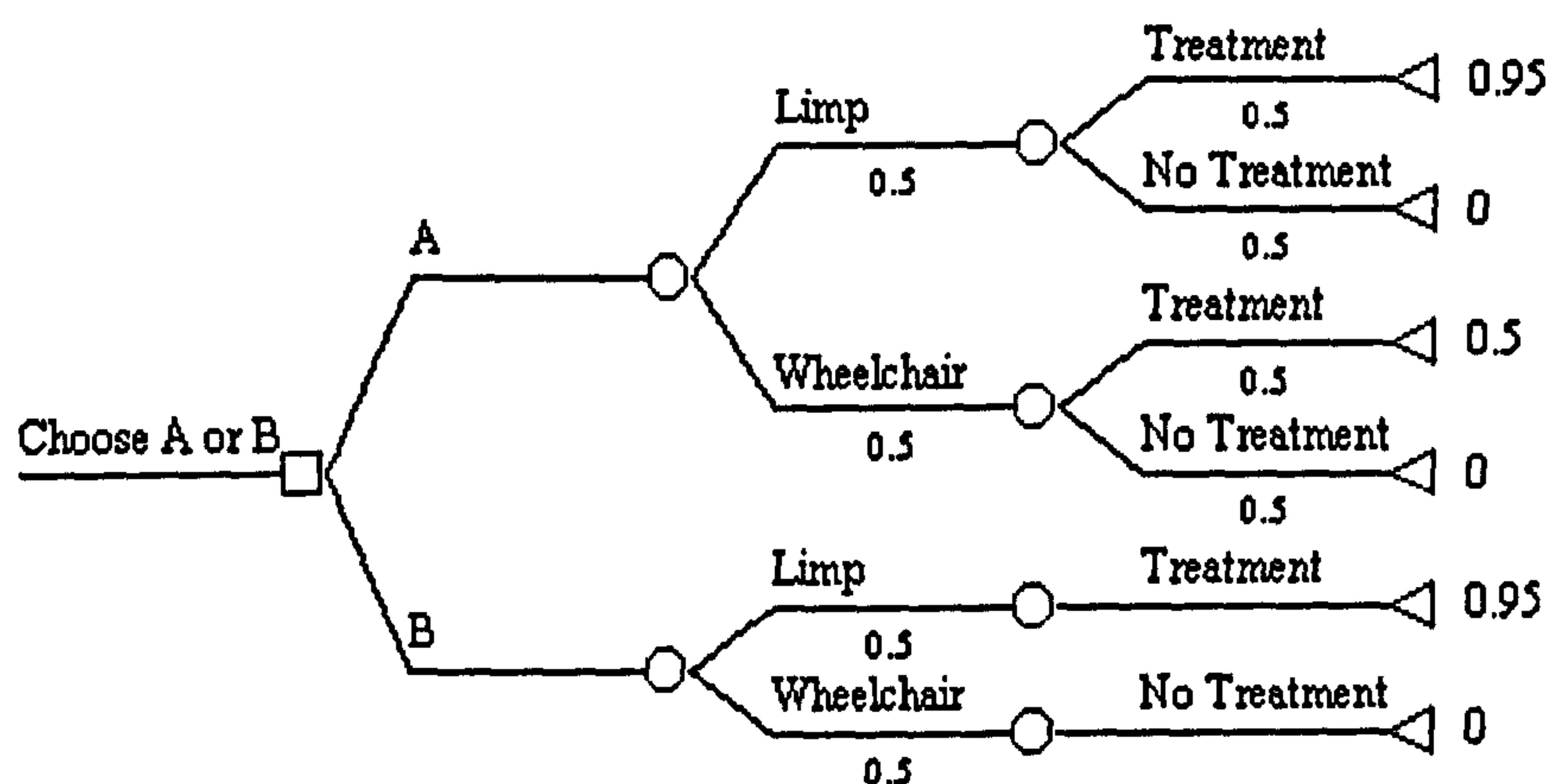


Figure 3.1: Decision Tree to illustrate the Scenario given by Singer *et al.* 1995).

Singer *et al.* assert that random choosing would be considered inferior to allocating treatment to the person with the potential to generate the greatest number of QALYs. Option A (random choosing) has an expected QALY value of 0.3625 $[(0.5 \times 0.5 \times 0.95) + (0.5 \times 0.5 \times 0.5)]$ for each year of survival. Option B has an expected QALY value of 0.475 (0.5×0.95) for each year of survival. Singer *et al.* effectively argue that Option B dominates Option A since in both cases there is an equal probability that once the veil is

⁷ The two examples referred to are on p.148-149 of the paper.

lifted (at the first set of chance nodes) you will not receive the treatment but if you *are* the one selected for treatment the gains are higher if you are the more healthy person.

There are however, several reasons why the rational egoist may not choose B, the QALY maximising option. Firstly, as has already been exemplified, QALYs are not equivalent to utilities and there seems no reason to think that the utility derived from continuing to live for a disabled person would be any lower than that derived by an able-bodied person. The concept of rationality Singer *et al.* wish to appeal to is that of maximising expected utility yet Option B equates only to maximisation of expected QALYs. The point is made in a different example by Singer *et al.* where potential patients differ in the intensity of “interest in continuing to live”. However, with the exception of those with suicidal tendencies the concept is of questionable coherence. In this situation, QALY maximisation fails because it is based on a disputed measure of outcome rather than the fact that it is consequentialist *per se*.

Secondly, maximising expected utility is not the only admissible interpretation of rationality. Rawls chooses the maximin principle as the decision rule from the original position⁸ and it is feasible that this rule would lead to random choosing in preference to the QALY maximising position. If we accept, as Singer *et al.* do, that *ceteris paribus* QALY differences equate to utility, then the decision rule of maximising expected utility supports Singer *et al.* Maximin evaluated in terms of final outcomes also supports the QALY maximising choice if conducted in terms of final outcomes (the worst payoff in either scenario is zero [death]). However, the decision rule of maximin is based on an assumption that the rational egoist is risk-averse. It is therefore conceivable that the relevant consideration is the remaining profile when the veil of ignorance is lifted. If

this is the case then Option B is in fact inferior to Option A since the worst pay-off is certain death compared to a fifty per cent chance of receiving the treatment. The claim is that whilst the rational egoist's choice *might* coincide with QALY maximisation it is not necessarily the case.

A third approach stresses the importance of the procedure by which individuals are chosen in this situation and may be appealing, in contrast to consequential approaches, particularly when the problem is conceived as a societal rather than individual patient problem. Evidence shows for example that individuals prefer approaches such as random choosing in contrast to more "economic" approaches when faced with certain types of social choices, see Frey and Bohnet (1995).

3.4 INTEGRATING ALTERNATIVE NON CONSEQUENTIALIST CLAIMS

The measure of health gain which the QALY embodies arises from a simple truth that individuals, whether from a patient or citizen standpoint, value health interventions both because of the effects of length of life and quality of life. This claim is not disputed here. However, for the reasons outlined above the framework for rationing given by this measure alone is considered insufficient in establishing a publicly acceptable framework. Furthermore, the issue is not one which can be overcome by reverting to alternative consequentialist frameworks, including utilitarianism, as favoured by some health economists. For example, those who favour cost-benefit analysis rather than cost-utility analysis regularly cite the welfare economic basis of the approach as grounds for its superiority. Issues of process utility and non-health benefits arising from health-care interventions can (and perhaps should) be included to provide a ranking of treatments but deontological issues are neglected by both. In what follows a number of

⁸ Harsanyi (1976) rejected maximin in favour of maximising expected utility on the grounds that maximin

non-consequentialist values are discussed in the context of rationing, highlighting the fact that QALY maximisation and utility maximisation (supported by advocates of ‘full’ cost-benefit analysis) fall together. It should be remembered that the discussion is not advocating a rationing framework that ignores outcomes. The issue is how best to integrate these potentially competing claims of which four types are discussed below.

3.4.1 Rights

Whilst the language of rights dominates both public and political debate in relation to rationing health-care services, particularly in the UK, relatively little research reflects this concern. Lenaghan (1997) and Bynoe (1997) are notable exceptions to this and both draw the crucial distinction between substantive and procedural rights. Substantive rights to particular levels of health-care for individuals experiencing particular conditions have proved difficult to define and enforce in the context of rationing health-care. It is only recently that cost considerations have been allowed to over-rule any perceived legal rights patients may have to treatments, see for example Drewett (1996). Instead Lenaghan has argued in favour of developing procedural rights to guarantee individuals access to fair and accountable decision-making processes. The argument for “rights incorporation” made here mostly reflects this latter type but the two are clearly not mutually exclusive.

Some philosophers, notably Jeremy Bentham, have questioned the need for reference to rights at all claiming that they exist only in terms of what the law decides to give citizens. Clearly, no individual or group can claim a right to any specific health-care intervention regardless of cost; despite the lack of legal consensus on this issue. However, the importance of rights talk cannot be entirely dismissed, particularly in the

context of health. The NHS does not represent only an attempt to achieve efficient health production in the face of market failures but is premised in part on the notion of some right to health-care and the same may be true of other publicly supported health-care systems.

The classical utilitarian position justifies rights in a purely instrumental manner, a means for achieving the end of maximising social welfare with no inherent value of their own, Sugden (1986). There are certainly many examples of rights which exist at least partly for their instrumental effects for example, property rights for the encouragement of productive activity. However, as Sen (1979) illustrates there are strong reasons for a 'goal-rights' based system, exemplified with the case of a gang of sadists who would derive pleasure from beating someone up. Sen's rejection of the utilitarian view is that irrespective of the utilities derived from the beating it would represent a violation of the victims rights. Furthermore, Sen objects to the constraint-based deontological view of rights. In this view, rights are afforded intrinsic value which over-rule any utilitarian concerns, effectively limiting the sphere in which maximisation of outcomes may be pursued. The view is one which both Nozick and Dworkin have advanced but is of no help in the example above to a third party seeking reasons to intervene and avoid the bashing occurring.

The view is appealing as it reflects the fact, advanced by Scanlon (1977), that rights are more clearly discussed outwith the utilitarian frame. Whilst it might be feasible to view rights in a consequentialist framework⁹, the result seems unnatural; rights and utilities in

⁹ The integration of process utilities has received significant attention recently, particularly by advocates of willingness-to-pay in preference to QALYs or other outcome measures (cost-benefit analysis rather than cost-utility or effectiveness analyses). Conjoint analysis is one method that has been used to establish the extent to which individuals (usually patients not the general public) are prepared to trade-off health outcomes in favour of other attributes of health interventions. Such studies generally aim to establish the relative strengths of health outcomes, non-health effects of interventions and processes in patient utility

this view represent incommensurable claims. Adler (1998) identifies three types of incommensurability in his discussion of cost-benefit analysis. His category of “esoteric ordering failure” refers to the type of incommensurability problem that is relevant in the current context. Conventionally, a trichotomy of relations are possible between competing options: one option is better, the other option is better, or they are equal. However, where this type of failure occurs it is not feasible to order options according to this trichotomy. Adler (1998) offers the following quotation from Sunstein which mirrors the objection to consequentialism and rights:

‘A simple or flat judgement that a mountain is “really worth” \$10 million is inconsistent with the way that we (or most of us) value the mountain. This is because the mountain is valued through a different kind of valuation from the \$10 million; the former produces awe and wonder, whereas the latter is for human use – though admittedly \$10 million may produce a (different) sort of awe and wonder as well. These points hold even if people might be indifferent between \$10 million and the mountain in the sense that they do not know which they would choose if both were offered...” (Sunstein, quoted in Adler, 1998, p.1377).

The links between outcomes and rights provide a useful insight into the reasons why rights might be of importance in establishing a publicly acceptable rationing framework. Consider the example of conjoined twins, where an operation exists to separate them giving a higher quality of life than in the joined state, but which carries with it a risk, p , independent to each that they will die. If the QALY score associated with joined life is 0.8 and life expectancy is equal whether joined or separated (subject to surviving the

functions, see for example Ryan (1999), San Miguel *et al.* (1997), Ratcliffe and Buxton (1999). One of the most frequent criticisms levelled at the willingness-to-pay literature in general and one which, I feel, is also relevant to the use of conjoint analysis in certain situations, is that the types of decisions respondents must engage in are those which are alien to them. At least when asking about rationing at the macro level, the technique does not seem to offer an acceptable method for incorporating rights (or any of the other deontological considerations discussed in this section).

operation) then the decision rule of QALY maximisation requires the operation to proceed if $2P > 1.6$ that is, the probability of survival is greater than 0.8. However, for the children's parents the situation may be viewed very differently. Total expected health maximisation sets priorities according to risk neutral preferences yet risk averse parents would see the operation less favourably. Maximising expected utility also assumes utilities are set according to risk neutral preferences and must therefore oppose the wishes of the parents. One way of supporting the decision that most would presumably support is to say that the rights of the parents to choose are relevant. This interpretation gives intrinsic value to the right to choose but is not simply a constraint to maximising outcomes. The rights of parents to choose the appropriate course of action for their children does not over-ride all considerations for expected health outcomes but is one of many competing claims that must be integrated¹⁰.

3.4.2 National Insurance, Taxation and Social Contracts

Whilst the National Health Service seems premised on equality of access regardless of ability to pay, it may not be entirely acceptable to divorce entitlements from financial contributions individuals have made. The claim is particularly relevant to the system of social insurance in the UK which was introduced by the post-war Labour government. The National Insurance program has developed from a scheme which was run as a fund into which the employed were obliged to contribute and from which those same individuals could draw when illness or old age required, Johnson and Falkingham (1992). National Insurance was therefore originally premised on the basis of the contributory principle and for many benefits the link remains explicit. Entitlements to state pensions and unemployment benefits for example, are conditional on the payment of insurance contributions.

¹⁰ The high profile case of the conjoined twins, Jodie and Marie, outlines the relevance of the rights based

For the elderly who have made (or whose spouses made on their behalf) National Insurance contributions effectively comprise an implicit contract with the state which, if honoured, must translate into higher priorities for treatment than a QALY maximising approach would allow. Recent evidence from Stafford (1998) finds continuing support for this contributory principle which would translate into higher priorities for all those who have made sufficient contributions, with certain exceptions¹¹. The opinions expressed in this study may be instrumentally utilitarian at least in part, since those who make contributions are generally more economically productive, but the dialogue of participants mirrors issues raised elsewhere in this chapter. For example, respondents believed that National Insurance contributors have a *right* to benefits and expressed concerns over the *fault* of those who have not.

As Peacock (1952) acknowledges, "...the adoption of the term 'insurance' by the proponents of social security was a stroke of promotional genius" and to attempt to undermine these principles now may not be acceptable. Whether the same opinions hold in relation to taxation in general is not clear (other than as an instrumental rule to ensure benefits accrue to the most productive members of society) yet the distinction may be of crucial importance in the context of future health-care rationing.

Other forms of taxation certainly have less claim to form binding social contracts to the degree that National Insurance contributions do. However, the effect of payment or non payment of taxation as a factor in the determination of public sector health-care

approach.

¹¹ The study provides qualitative evidence on behalf of the Department of Social Security and found general support for the contributory principle. NHS entitlements were not considered, the focus was on three contingencies: unemployment, sickness and retirement.

entitlements (or to any other publicly provided goods if media reports are anything to go by) are not trivial to most individuals.

3.4.3 Voice and Procedural Preferences

Going beyond consequentialism implies that social decision-making has an intrinsic value, beyond that which exists for instrumental purposes. Suzumura (2000), highlights the point with a quote from Arrow (1951):

“Among the variables which taken together define the social state, one is the very process by which the society makes its choice. This is especially important if the mechanism of choice itself has a value to the individuals in the society. For example, an individual may have a positive preference for achieving a given distribution through the free market mechanism over achieving the same distribution through rationing by the government. If the decision process is interpreted broadly to include the whole socio-psychological climate in which social decisions are made, the reality and importance of such preferences, as opposed to preferences about the distributions of goods, are obvious.” (Arrow, 1951, pp.89-91.)

This chapter focuses on one dimension of the decision-making process; voice¹². Voice refers to the ability of an individual to contribute to the decision-making process either directly or by representation. Voting is one means by which this procedural right can be exercised and is (said to be) an important part of democracy. Relevant to the issue of health-care rationing, citizens have rights to express views concerning the kinds of treatments that should be provided by the state, even though these rights are rarely

¹² Procedural preferences are examined in great detail in Chapter 4.

exercised directly. Direct action (beyond occasional demonstrations against expenditure cuts) is still rare, though district health authorities are increasingly using focus groups and surveys to determine priorities while media coverage of particular cases serves to elicit, and perhaps shape, views on rationing principles in certain specific areas. Furthermore, lay representation is common within health service decision-making bodies such as Primary Care Groups (PCGs) and NICE.

Whether moral or otherwise, the acknowledgement of public opinion does have a normative value that may lead to conflicts with health maximisation. However, returning to the initial exclusion problem, it is easy to see that rational egoists would vote for treatment for members of the group to which they belong (assuming they knew which group they were in but not whether they themselves would actually contract a disease). Treatment would then go, not to members of the group first afflicted, but to members of the largest group resulting in exclusion - albeit possibly of a different group and for different reasons. The view is that exclusion on the basis of votes has no more fairness than exclusion on the basis of QALYs and that this is the tip of an iceberg. Majority voting for a system which systematically discriminates against the needs of certain groups would lead to an unfair distribution of health-care resources, however democratic. Nevertheless organisations need public support if they are to perform their functions and this has led to the employment of a variety of needs assessment methodologies (including qualitative methods such as focus groups). Recent survey evidence, for instance, reported by economists Frey and Bohnet (1995) finds that process oriented mechanisms (c70% of their sample preferred negotiation) are preferred to decisions based solely on expert opinion and that use of economic measures like willingness-to-pay are least popular of all (acceptable to 20%).

3.4.4. Communitarianism

Communitarianism developed as a response to problems in liberal philosophies. It sets itself against rights (Etzioni (1995) calls for a decade long moratorium on the creation of new rights) and emphasises three things: the concept of the self, political epistemology and the importance of communities, Bell (1993). Humans are conceived of as social animals with high social needs about which individualistic theories (e.g. Nozick (1974)) have little to say. Political philosophies are regarded as being located within a particular time and place which makes the search for a unique timeless framework (like utilitarianism) seem inappropriate.

As communitarianism undercuts the value of individual rights it is tempting to think that it might remove some of the constraints on health maximisation imposed by rights. In one sense it is difficult to tell, as health maximisation and communitarianism are such different kinds of theories that a comparative evaluation is not easy. It could be that health maximisation is not a universal account of health-care rationing but one that suits the UK at this point in time. Further, it allows for the aggregation of preferences in determining trade-offs between expected life years and quality adjustments via the construction of the QALY measure so it might be said to have a social aspect to it. However, communitarians emphasise the importance of exchange between individuals and the local communities to which they belong. Individuals have duties to their communities, (which might well extend to minimising activities like smoking that might impose unnecessary costs on their communities) while at the same time communities value family units and act to preserve their structure. Respect for the elderly, for instance, might mean that their health is given a priority that is not sufficiently reflected in the QALYs the elderly generate. In other words communitarians might want to provide or withdraw health for reasons that are more comfortably accommodated

outside health maximisation. The emphasis on duties is as non-consequentialist as is the emphasis on rights.

The implications of communitarianism for health-care rationing have yet to be elaborated by those who advocate the doctrine. However, the doctrine is interesting in the context of this paper as it represents an emerging philosophical framework that is anti-rights and yet still suggests reasons why one might want to temper the entitlements defined under health maximisation.

3.4.5 Theoretical Overview

The issues outlined in the previous two sections together suggest that any normatively acceptable rationing guidelines must integrate concerns which span several frameworks. The main items discussed are consequences, rights, votes and social contracts. For empirical purposes, it is also important to factor out variables that may play a role in determining entitlements whether they are of normative significance or not - lobbying and the opinion of medics are two such variables illustrated. Because health maximisation deals only with one of these frameworks it is insufficient and whilst other consequentialist frameworks may be capable of addressing certain criticisms, for example, by weighing QALYs to take account of distributive equity considerations, the fundamental reasons for wishing to do so are non-consequentialist. Only non-consequentialism deals with all the issues of concern to health-care rationing and, furthermore, these claims may be incommensurable with outcomes such as QALYs or utilities.

Existing survey evidence supports the primary argument; QALY maximisation is only appealing in certain contexts, see for example Nord *et al* (1995). However, concerns

with the normative validity of QALY maximisation should not be associated with concerns about the contribution of an economic approach to rationing *per se*. If one accepts that a rationing agency might not need to adopt one approach lock, stock and barrel, then the moral theories reviewed should not be regarded as competitors but rather as complementary parts of a framework that integrates different kinds of claims. The conceptualisation of rationing as a synthetic task shows that the rejection of a *decision rule* like QALY maximisation is perfectly compatible with the use of *outcome measures* like the QALY. The survey evidence which follows adds to existing evidence relating to QALY maximisation and provides empirical evidence for alternative, non-consequentialist claims in determining health-care entitlements.

3.5 EMPIRICAL EVIDENCE

3.5.1 Motivation and Links to Theory

Health-care entitlements, it has been argued, should be functionally dependent on consequences, rights, votes, actual social contracts and community values. The decision rule of health maximisation focuses on just one of these which is why the doctrine seems so alien to many. The validity of these non-consequential criticisms of health maximisation and the level of support for alternative claims which have been advocated are tested in the following sections using a self-administered, anonymous, postal questionnaire. It identifies elements of frameworks that the public believe are important and that should be integrated into a framework which includes concerns for consequences in order to establish a publicly acceptable rationing mechanism.

The empirical results relate to a number of the conceptual links between QALY maximisation, its problems, and the alternative claims that have been discussed above. First, evidence is provided relating to the problem of arbitrary exclusion and people's

concern for equal treatment for those in equal need. Second, data that shows many people believe that extending the health-care benefit to incorporate various utilities, as certain utilitarians might require, is inappropriate. Third, I provide evidence that indicates many people are sensitive to information about causes and duties, as non-consequentialist theories suggest might be appropriate. Fourth and finally, evidence is provided that sheds light on the extent to which people believe health-care rationing is a social choice about which voter-related information should be collected.

3.5.2 Survey Design and Methods

Questioning the public on an issue which is particularly sensitive and controversial, such as health-care rationing, is subject to a number of potential problems. The issue is not one that is consistent with the everyday choices made by individuals and the options presented can therefore seem somewhat alien. Responses are made on the basis of a number of complex issues covering ethical and moral attitudes and concerns have therefore been raised about the validity of competing data collection methods, see for example Dolan *et al.* (1999). A postal survey was used here as a means of collecting data for a combination of reasons relating both to the financial limitations of the research project and the validity of the method. However, the avoidance of a number of potential biases was paramount in the design of the data collection tool.

Specific framing issues are dealt with separately in subsequent sections but some general points about the survey design are appropriate here. Firstly, the survey was piloted using three variations of the questions before arriving at the final instrument. These pilots were used mainly to address individual question wording, see for instance Moser and Kalton (1971) and Dillon (1990), but issues such as the order of questions and response rates were also examined.

It was decided that none of the questions should mention costs directly but control for this by making it clear that potential patients differ only in terms of the criteria mentioned in the situation descriptions. This approach was decided on in order to avoid overly complex descriptions whilst still controlling for this obviously crucial component in decision-making. It is recognised that respondents may have faced similar difficulties to those mentioned above in relation to conjoint analysis type questions although feedback at the pilot stage supported this approach. Questions were also constructed so as to ensure as neutral a description as possible. In some cases this was achieved by using the phrase “some people might argue that...” to reduce bias arising from perceptions of what might be socially acceptable answers, although in many cases all possible responses could be argued to be socially desirable by different theories of welfare. Options were also described in as symmetrical a manner as possible although this was balanced against the need to avoid excessive repetition. Dillon (1990) has shown that more reports of socially undesirable behaviour are elicited by open form questions but this approach was rejected since this was not considered a major concern and such questions do not generate data appropriate for quantitative analysis. Were this not the case, a qualitative analysis based on data from face-to-face interviews or focus groups might be more productive. In most cases respondents were offered both “don’t know” and “equal preference” options so that preferences were not forced where none existed. The introduction of “don’t know” options has been shown to reduce agreement with other substantive options. The use of a postal survey, as opposed to alternatives such as face-to-face interviews or one-off focus groups, allows respondents a long period to consider their opinions whilst the instrument used still allows respondents to indicate being undecided. A major source of potential bias was therefore minimised by

these actions, although it was found that very few respondents checked the “don’t know” options when given the option.

The final version of the survey¹³ was sent out to a sample of Leicestershire residents drawn from the electoral register. This was considered the most reliable and up to date sampling frame which was relatively easily available and contained sufficiently accurate postal addresses. A usable response rate of 31% was achieved ($n=144$). A covering letter was also sent which introduced the concept of rationing/priority setting. As a result of feedback from the pilot surveys it also explicitly stated that the study was not related to determining the level of funding for the National Health Service.

The work is primarily driven by the theory of QALY maximisation and attempts to identify the proportions of the population who agree with particular related opinions¹⁴. Respondents were asked to indicate a number of socio-economic characteristics to allow this to be achieved. Exact, binomial confidence intervals (C.I.s) are reported where appropriate, Armitage and Berry (1994), and are used to indicate the boundaries of proportions of respondents agreeing with specific frameworks.

3.6 RESULTS

3.6.1 Socio-Economic Characteristics of Sample

Respondents were asked to report details on four dimensions of socio-economic status in order for checks to be made on the representativeness of respondents to the population (Leicestershire residents). Responses to these questions are reported in table 3.2. Also included as a means of comparison are results from the 1994/95 General

¹³ A copy of the survey instrument, together with the covering letter used is shown in Appendix 3.1.

¹⁴ In their discussion of the particular problems associated with opinion surveys, Moser and Kalton (1971) identify two kinds of responses: the first tries to estimate (and put bounds on) the proportion of a

Household Survey (GHS). These calculations were made after excluding all respondents aged under 16. Due to the fact that an individual must be aged 16 or over to appear on the electoral register and that the list used was compiled in October 1996, nine months previous, there is a slight under-representation of those aged under 18 in our sample. The sample also shows a lower proportion of respondents in the age range 26-45 years and a higher number in the category 46-64 years, in comparison with the GHS. There is a significant under-representation in the sample of those in the highest income category (over £25000 per annum) whilst other income categories reflect a relatively close alignment with respondents in the GHS. Notable differences occur within occupational categories, the most prominent of which is the proportion of retired persons which is lower in the GHS. Differences in other occupational categories do not exceed 5%. Further information included in table 3.2 for comparative reasons is from the 1997 general election results for Leicester¹⁵. Our sample indicates a proportion of 57% of respondents voted for the Labour party in the last election, whilst only 11.1% and 10.4% voted for the Conservatives and Liberals respectively. Whilst this would appear to be a major bias in the sample, election results indicate that this is not excessive. Labour voters are over-represented only by a 10% margin whilst the variation between sample results and general election figures does not exceed 5% for the other parties. Whilst the decision to return a usable questionnaire was a self-selected action there appears to be no major bias in this sample which is evident in the responses to the four socio-economic dimensions tested.

population who agree with a particular opinion whilst the second asks individuals a series of questions in order to provide an overall measurement of attitudes

¹⁵ Source: Press Association.

3.6.2 QALY Maximisation and Arbitrary Exclusion

In this section of the survey the extent to which respondents agree with QALY maximisation as a rationing device is tested by using age differences between groups of patients as a proxy for health gain. Whilst there is existing evidence to suggest that there is limited support for rationing by age¹⁶, questions here explicitly test health maximisation by controlling for factors such as prognosis after treatment.

Respondents were asked to consider how funds should be allocated between two kinds of disease if it were not possible to treat all those affected when patients differ only in age. Whilst uncertainty may be characteristic of medical decision-making in practice it was decided to abstract from this for reasons of clarity. QALY issues were further exaggerated in the decision problem by equating treatment with full recovery, including normal life expectancy, and lack of treatment with death. Four options were presented.

‘QALYMAX’ (QALY maximisation) is where all resources are used to treat those in the lower age group first with those in the older group receiving treatment only if there are funds left over.

‘FAVYOUNG’ entails allocating more resources to the treatment of the disease which affects the younger group. It does give a degree of preference to the younger group and consequently does reflect a concern for health outcomes but does not necessitate the complete exclusion of a patient group from health-care entitlements on grounds of age,

¹⁶ See for example Nord *et al.* (1995) for survey work in Australia, Kuder (1993) for focus group evidence in USA. Bowling (1996) does include the topic of age in her survey work based in the UK but questions are not controlled in such a way that implications for QALY maximisation can be drawn. Lewis and Charny (1989) offered a sample of Welsh voters choices between individuals differing only by age and found that, in two of the three examples, there was support for treating the younger patient. However, respondents were discouraged from choosing equal priority. Furthermore, in the example which had the smallest difference in age between the two individuals (35 year old versus a 60 year old), over half of those who chose to allocate resources to the younger patient reported doing so only with difficulty. Interestingly, in their third example, voters preferred to treat an 8-year-old in preference to a two-year-old in line with DALY methodology.

which may be seen as somewhat arbitrary, as would occur with a health maximising approach.

‘EQUAL’ indicates the option of equal allocation of resources between the two diseases.

‘DON’T KNOW’ was also included for the undecided.

Initially respondents were asked to choose between groups where age differences were large (80 years versus 40 years). This differential was gradually reduced until groups differed by just one year (41 years versus 40 years). One would expect support for health maximisation to be more likely where age differences are largest and, given the potential for respondent anchoring, this was the first question presented. If anchoring does prevail in this context, the question format will therefore favour QALY maximisation. Results are shown in table 3.3.

Some of the more obvious, or at least commonly used statistical tests (chi and z) are not strictly applicable in this situation as responses to questions are not independent. Therefore, a replicated measures test, the Cochran Q test, was used for differences between proportions in k (greater than two) related samples with categorical or naturally dichotomous data (Siegel and Castellan, (1988, pp.171). Using p to denote the proportion of subjects choosing in a way that is consistent with QALY maximisation and subscripts in an obvious fashion, the following was tested, $H_0 : p_{80} = p_{70} = \dots = p_{41}$ vs $H_a : H_0 \text{ false}$. The test statistic, Q , has a value of 58.90 and is approximately chi-squared distributed with $k-1$ degrees of freedom when $n \geq 4$ and $nk \geq 24$. As $n = 144$ and $k = 5$, both conditions are met. We can, therefore, reject the possibility that the answers to the different versions of the question are drawn from the same population. A more approximate approach to the data here would be to note that in all five variants, the percentages of those choosing in a manner consistent with

QALY maximisation, as evidenced by the confidence intervals and as is discussed below, are always closer to 0% than 100%.

Those concerned purely with health maximisation must choose option one in all situations, irrespective of the size of age differences. The decision problem was described such that even where the age differences may be small, failure to choose this option involves a deliberate and clear sacrifice of QALYs. Results show that support for such an approach is limited. Even in the first scenario, where one would expect support for QALY maximisation to be strongest since the age difference between the two groups of patients is largest, 95% confidence intervals indicate that the proportion of those rejecting this approach ranges from 76% - 89%. Furthermore, as age differences are reduced the proportion of respondents not agreeing with QALY maximisation increases. This reaches a maximum range of 96% - 100% at a ten year age gap. These figures indicate an overwhelming rejection of the health maximising approach. Respondents generally do not agree that age should be used as a rationing device even when there are large differences between groups and therefore large differences in potential life years saved (or lost). A similar pattern is found when examining the number of respondents opting for the intermediate 'FAVYOUNG' option with a significant level of support (19%) where age differences are largest, falling to zero when ages differ by just one year.

Whilst these results indicate a rejection of the health maximising approach to rationing they should not be seen as demonstrating a complete lack of concern over health outcomes, particularly when age differences are large. The sample mean, indicating the proportion of respondents rejecting any skewing of resources based on age, is 0.6429 (95% C.I.s, 0.56-0.72) when the first group are aged 80 years old. Although sample

means increase dramatically as the age of the first group of patients is reduced, responses indicate that the proportions of those indicating any concern for health outcomes is also significant. To further understand these data, a confirmatory cluster analysis¹⁷ of the responses to these questions was conducted. It was hypothesised that there might be three groups of respondents: strict QALY maximisers who preferred to treat the youngest in all cases; strict 'equal righters' who preferred to allocate funds equally between diseases affecting younger and older groups; and 'trade-offers' who would increasingly prefer QALY maximisation to equal priority setting as the QALY difference got larger. The results of this analysis appear in Figures 3.2 (a through e). What was found is that the largest of these three groups is in fact one that looks like the postulated 'equal righters' group. Two smaller clusters can also be identified, although these two groups only depart significantly in their choices from equal priority when the QALY difference is large. Cluster 1 comprises a distribution of people, though the modal choice is to allocate resources to both diseases but more to that which affects the younger patients. Cluster 3, which is slightly smaller and more homogenous than cluster 1, comprises mainly people who support QALY maximisation when the QALY difference is great. However, notice that this cluster is not equivalent to the postulated QALY maximisation group as members of it switch to equal priority as the QALY differences between the groups diminish.

3.6.3 Limited Appeal of Forms of Consequentialism

The term health maximisation has often been used in a positive prescriptive sense, despite the fact that there is not the same philosophical tradition of argument in its favour as there is for utilitarianism. This section tests four competing types of consequentialism that are derived from utilitarianism in that they widen concern away

¹⁷ Ward's technique for assigning members to clusters, Everitt and Dunn (1991).

from the individuals health (which is the concern of QALY maximisation) towards a more utilitarian metric which would include the welfare of all actors affected by a medical procedure, rather than the individual patient.

As noted earlier, potential confounding influences were controlled by an explicit instruction to subjects to treat patients as being equal in all respects other than those which appeared in the question. However, included from the beginning of this section was the general statement that patients are similar in all aspects other than those specified. This served as a security measure against response bias without making the questions excessively repetitive or lengthening the survey. Results are shown in table 3.4.

The first question in this section asks whether a broader measure of outcome than the health or utility of an individual patient should be used in determining entitlements to health-care. Results indicate a sample mean of the proportion of people disagreeing with personal utilitarianism of 0.88 (95% C.I., 0.81-0.93). Despite the magnitude of responses favouring equality of access for patients irrespective of the effect on personal utility, there is still a greater degree of support for this type of consequentialism than the other more inclusive types tested in this section.

The three other questions included in this section were concerned with consequences outside the individual sphere. Choices were offered between patients who differ only in marital status (Spouse utility), whether they have children (family utility), or income (referred to as economic utilitarianism). Options presented corresponded with a consequentialist ideology, an anti-consequentialist view, and an egalitarian view.

Firstly, when faced with a choice between a married and an unmarried person, the proportion of those who disagree with giving priority for treatment to the married person, as indicated by the sample mean, is 0.97 (95% C.I., 0.92-0.99), indicating an overwhelming rejection of this type of consequentialism. Another criticism of the health maximising approach to prioritising health services is that it does not incorporate the effects on a patient's dependants. Respondents were therefore presented with a choice between patients with and without children. A proportion of over 0.93 of respondents disagreed with the view that those with children should be given a higher priority than childless patients (95% C.I., 0.88-0.97), opposing the choice advocated by a consequentialist decision rule. Economic welfare was the broadest consequence respondents were asked to consider. In this question a choice between high and low wage patients was presented. In the absence of market failures, economic consequentialism advocates prioritising services for high wage earners yet our estimates show confidence intervals of the proportions rejecting this approach between 96% and 100%. Interestingly, the option to give priority to low wage earners received a significant degree of support (10%). Not only does this reinforce the strength of opinion against rationing by economic consequence but may also indicate that the concept of access to health services according to need should incorporate the ability to pay for such services privately.

Results in this section indicate that attempts to find a publicly acceptable rationing device based solely around a utilitarian philosophy are likely to be normatively unappealing. Indeed, when compared to results concerning the QALY maximising approach (where age differences are largest) each of these alternatives based on broader consequences receives a lower level of support. It therefore appears that QALY maximisation is not deficient due to the nature of the consequence (health) that is its

sole concern, but because of its consequentialist nature *per se*. An acceptable rationing framework must incorporate broader concerns than QALY maximisation but these concerns are not consequential in nature. Subsequent sections of the survey test the acceptability of alternative claims that may complement concerns for outcomes such as health gains.

3.6.4 The Relevance of Causes

Health maximisation focuses only on outcomes in terms of health. In common with all brands of consequentialism, it is blind to the underlying reasons for these outcomes. The focus here is on the extent to which health-care entitlements are affected by how treatment needs came to be generated. Questions are asked both in terms of specific conditions and with respect to risky behaviour in general. In each of the scenarios presented questions ask about priority setting between groups of patients suffering from the same condition such that the expected health gain from receiving treatment would, on aggregate, be the same for both groups. Results are shown in table 3.5.

Question one asks if priorities for treatment should differ between HIV positive persons who have become infected through the use of illegal intravenous drug use (and *may* be seen as responsible for their condition) and those infected through contaminated blood transfusions. Confidence intervals at the 95% level indicate that the proportion of those advocating preferential treatment for those infected through contaminated blood transfusions (and therefore rejecting a pure health maximising policy) ranges from 50% to 68%. A slightly lower proportion of respondents accept that cause is relevant in scenario two which presents choices between smokers and non-smokers requiring treatment for lung cancer. Confidence intervals in this situation indicate that the proportion of those choosing for non-smokers to receive a higher priority for treatment

than smokers ranges from 38% to 56%. These results show that, in these specific situations, health maximisation is unpopular as it is blind to how health gains are generated.

Question three presents a similar situation in very general terms. Two groups of patients require medical treatment in a situation where there are insufficient funds to treat all those in need. One group require treatment as a result of engaging in risky behaviours whilst the other group are suffering as a result of events beyond their control. Respondents are asked to consider whether or not the cause of disease is relevant to the priority for treatment that patients should receive. In this general situation there is a slightly higher level of agreement with viewpoint that patients in each group should receive an equal priority, as consistent with consequentialism. The proportion of respondents indicating that the cause of disease is relevant in this general case, as indicated by the sample mean, is 40% (95% C.I., 0.32-0.49).

In order to provide a comparison, question four frames the problem in an area outwith the health service. Respondents were asked to consider whether mountaineers should be obliged to take out insurance to cover the costs of any rescue services they may require. This situation is similar to that faced in the health service but was included to identify differences in opinions between the NHS and other services supported by resources provided by a combination of public and voluntary sources. Results show that there is a far greater level of support for non equal access to such services than in the health sector. The sample mean of the proportion of the sample supporting compulsory insurance is 0.85 (95% C.I., 0.78-0.91).

Results in this section as a whole indicate that there is a moderate level of support for allocating priorities to patients on grounds other than expected health gains. Respondents are concerned with how health-care needs are generated and are prepared to discriminate against those who fail to take precautions to protect their own health. The significance of this rejection of consequentialism, and therefore QALY maximisation, is particularly important given the framing of the questions. In each of the scenarios presented, equality of opportunity for patients equated to a health maximising viewpoint. Given what we know about attitudes to the NHS this meant that the questions were biased in favour of the health maximisation standpoint. This effect is apparent from the results gained in question four which show a greater level of rejection for the QALY maximising approach outside the immediate health service. Yet despite this results indicate a high level of support for cause relevance. Two supplementary questions in this section address this bias by framing the issue in an alternative manner. Both questions present a situation where two groups of patients are suffering from similar conditions but have differing life expectancies. In the first instance this is due to economic status, with those from a wealthy background enjoying a higher life expectancy. In the second case, the patient group with lower life expectancies lead lifestyles that are generally considered to be risky for health. In each of these scenarios, QALY maximisation advocates allocating priority to the group with the higher life expectancy. Results however, show an overwhelming rejection of the QALY approach. Not one respondent opted to allocate a lower priority to the lower income group in order to generate greater health gains, with the majority opting for equal treatment of both groups. There were however, a small proportion (8%) who expressed a preference for the opposite view, that is, to give a higher priority to the low income group.

Similarly, in the second question in this section, there is little evidence of a willingness to adhere to the position advocated by the health maximising approach when this entails giving priority to a group of patients with healthy lifestyles. 95% C.I.s indicate that the proportion of persons holding a view that contradicts QALY maximisation is in a range from 87% to 96%.

Finally, an analysis of the impact of socio-economic variables on responses was conducted. Only evidence of a link with political affiliation was established, see table 3.6.

Given that three cells in table 3.6 have expected values of less than 1, it was considered appropriate to drop the 'other' category for political affiliation in order to conduct a chi-squared test. The test result was statistically significant at the $p=0.001$ level indicating that the distributions are not independent.

Overall a strong rejection of the QALY maximising decision rule has been demonstrated. Whilst these questions cannot isolate the reasons for this rejection, it seems reasonable to suggest that this is due to concern with the way in which expected health gains are generated. The most likely confounding factor in this section is the egalitarian nature of public attitudes to the NHS which has been addressed both by including a scenario dealing with a similar issue outwith the NHS and by equating QALY maximisation variously with equality and inequality of access.

3.6.5 Votes/Public Opinion

Table 3.7 shows responses to questions concerning citizens procedural rights in health-care. Respondents were asked to consider the extent of their agreement/disagreement with three types of consultation process. The first two of these refer to methods of

measuring public opinion, namely public consultations such as citizens' juries, and voter surveys. The third question asked if health services should aim to mirror the configuration of services that would be provided by a market based system. This question was loosely based on the hypothesis that some individuals might see this as an alternative method of interpreting individual preferences.

Results show that there is general support for both forms of public consultation with point estimates around 2.4 (95% C.I., 2.3-2.6), where 3 is equal to neutrality and lower numbers represent agreement. This indicates that there is general support for health authorities involving the public in rationing decisions and that the form of consultation does not significantly alter the level of this support. Average opinion is slightly against distributing resources in a similar manner to private markets, with results indicating a point estimate of 3.3 (95% C.I., 3.2-3.5).

Table 3.8 shows results relating to two questions which ask respondents to consider how health priorities should be decided when there is a conflict between health maximisation, voter opinions and the rights of individual patients. The concern in this situation is with the identification of rights based entitlements to health-care without necessarily involving a trade-off with health outcomes and indeed, as previously suggested, it may be possible to judge outcomes in terms of their rights based implications.

The first of these questions presents a situation where a health authority must decide on the priority for a disease which affects only members of an ethnic minority group, meaning that there are relatively few voters advocating a high priority for this condition since they are unlikely to be at risk. The question does not directly specify the efficiency

of available treatments since pilot studies revealed that this did not influence responses and only complicated the question. There are no grounds for rejecting treatment provision on health maximisation grounds. 95% confidence intervals indicate that the proportion of those who think the health authority should respond to public opinion and give this condition a low priority ranges from 8%-20%. There is, therefore, general agreement with the option supported on health maximisation grounds, although a rights based argument is suggested below for these responses.

The second section presents an alternative decision problem in which voter opinion is in direct conflict with clinical opinion. Respondents are asked to consider whether a health authority should provide a treatment which has a very low expected health gain and is therefore not supported by doctors, but which the public have said should be provided. In this scenario, results illustrate a much higher tendency for respondents to disagree with health maximisation with confidence intervals range between the 50% and 68 % levels.

The difference (statistically significant) between the results gained in these two questions yield important insights into the role of rights in the rationing debate. It is clear that health maximisation or voting alone, cannot explain these results. One explanation for these results is grounded in health-care rights. Firstly, broad support for a rights maintenance approach to rationing is exhibited. Respondents are generally willing to reject the option favoured by voters in question one when this would entail the violation of the rights of a specific group (an ethnic minority). This trend is reversed in the second question where there is a much higher level of agreement with voter opinion rather than health maximisation since the former option entails the provision of the service. Secondly, I argue that the results suggest a possible judgement of outcomes

in terms of their implications for group rights. Question one in particular parallels Sen's theory of capability rights, where the outcome of providing treatment may reflect concerns for equality of access for different groups, specifically ethnic minorities, rather than a concern with health maximisation as a value in itself.

3.7 CONCLUDING REMARKS

The chapter provides arguments for, and supporting evidence of, deeply anti-QALY maximising preferences in the context of health-care rationing. The inability of adults to produce expected health gains, even at the age of 80, has for many voters surveyed, no impact on entitlements. On the other hand, evidence suggests, in the aggregate, that entitlements are a weak function of age so it would seem that any approximately true positive theory of normative judgements must include concerns for health outcomes as a component.

Similar anti-utilitarian attitudes are identified in the sample which lends credence to the primary hypothesis of this thesis; that QALY maximisation is rejected by individuals due to its consequential basis. Rationing frameworks that are based on alternative outcome measures to health maintain this underlying philosophy and therefore fall together.

Each of the alternative, non-consequential claims identified received a substantial degree of support from this sample. Whilst outcomes matter, so do rights, duties and beliefs about due process. Procedural fairness, particularly rights to representation and consultation, are of more importance to many respondents than attempting to mimic the outcome of an efficient market system. This is a theme which is further developed in the proceeding chapter.

Some of these findings add to existing evidence in the health economics literature, reviewed in chapter 2. The contribution of this work however is that it identifies those objections to health maximisation that exist for non-consequential reasons.

The primary implication of these findings is that respondents preferences reflect pluralistic tendencies, that is, consequential and deontological considerations require integration in a single framework. It also helps illustrate the practical relevance of the theoretical concerns about welfare economics that have been articulated most prominently by Amartya Sen. His theory of capability rights is the only theory currently discussed by economists which performs such an integration task and future work that attempts to operationalise these findings may benefit from the recognition of this link.

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TABLE 3.1

THE ARBITRARY EXCLUSION PROBLEM

	Group X	Group Y
Group Size	n_x	n_y
Proportion Affected	p_x	p_y
Age at which Disease strikes	a_x	a_y

TABLE 3.2

SOCIO-ECONOMIC DETAILS OF SAMPLE

	Male		Female		Total		GHS ¹⁸
	N	(%)	N	(%)	N	(%)	
<i>A. Age (yrs)</i>							
<18	0	0	2	1.4	2	1.4	3
18-25	5	3.5	12	8.3	17	11.8	10.8
26-45	23	16	14	9.7	37	25.7	38
46-64	25	17.4	31	21.5	56	38.9	27
>65	18	12.5	14	9.7	32	22.2	19.9
<i>B. Gross Household Income (£'s per annum)</i>							
< 5000	12	8.3	23	16	35	24.3	18.8
5000 - 16000	30	20.8	31	21.5	61	42.4	37.9
16000 - 25000	15	10.4	13	9	28	19.4	19.6
> 25000	10	6.9	4	2.8	14	9.7	23.6
<i>C. Occupation</i>							
Employed	37	25.7	32	22.2	69	47.9	55.5
Self Employed	3	2.1	0	0	4	2.8	7.4
Unemployed	7	4.9	6	4.2	13	9	6.4
Retired	22	15.3	22	15.3	44	30.6	22.0
Other e.g. student, housewife	2	1.4	12	8.3	14	9.7	14.7
<i>D. Vote in 1997 election</i>							
Conservative	5	3.5	11	7.6	16	11.1	16.1
Labour	47	32.6	35	24.3	82	57	46.3
Liberal	9	6.3	6	4.2	15	10.4	7.7
Other	0	0	1	0.7	1	0.7	-
<i>Total</i>	71	49.3	73	50.7	144	100	

¹⁸ Figures for age, income and occupation are taken from the General Household Survey of 1994/95. (n=18237). Voting behaviour taken from 1997 general election results, Leicester wards.

QALY MAXIMISATION.

<i>Question number and age differences (yrs)</i>	<i>Mean¹⁹</i>	<i>95% C.I.'s</i>	QALYMAX		FAVYOUNG		EQUAL		Don't Know	
			N	%	N	%	N	%	N	%
Q.5i 80 vs. 40	0.84	0.76-0.89	23	16	27	18.8	90	62.5	4	2.8
Q.5ii 70 vs. 40	0.89	0.82-0.93	16	11.1	27	18.8	98	68.1	3	2.1
Q5.iii 60 vs. 40	0.97	0.92-0.99	5	3.5	15	10.4	123	85.4	1	0.7
Q5.iv 50 vs. 40	0.99	0.96-0.99	1	0.7	4	2.8	138	95.8	1	0.7
Q5.v 41 vs. 40	0.99	0.96-0.99	1	0.7	0	0	142	98.6	1	0.7

QALYMAX – funds used to treat younger group first

FAVYOUNG – more funds used to treat younger group than older group

EQUAL – equal funds used to treat each age group

¹⁹ Means and confidence intervals are based around a coding of QALYMAX = 0, other responses = 1.

TABLE 3.4

VARIETIES OF CONSEQUENCES.

Question number and subject	Mean ²⁰	95% C.I.s	Consequentialist		Anti- consequentialist		Egalitarian		Don't Know	
			N	%	N	%	N	%	N	%
Q.4 Personal Utility	0.88	0.81-0.93	15	10.4	n/a ³		111	77.1	18	12.5
Q.2 Spouse Utility	0.97	0.92-0.99	5	3.5	1	0.7	137	95.1	1	0.7
Q.1 Family Utility	0.93	0.88-0.97	10	6.9	2	1.4	131	91	1	0.7
Q.3 Economic Utility	0.99	0.95-1.00	2	1.4	14	9.7	126	88	2	1.4

Notes

1. Key to questions:
 - “Personal utility” – patient with high vs. low enjoyment of life
 - “Spouse utility” – patient with vs. without spouse
 - “Family utility” – patient with vs. without children
 - “Economic utility” – patient with high vs. low wages
2. Key to responses:
 - “Consequentialist” – priority to patient generating higher utility
 - “Anti-consequentialist” – priority to patient generating lower utility
 - “Egalitarian” – equal priority to patients

3. This option was not considered relevant to this question.

4. Though the main interest is in the fact that mean proportions, as indicated by the confidence intervals, are nowhere near 0 as they would have to be if “consequence maximisation” held, the test $H_0 : p_{PU} = p_{SU} = \dots = p_{EU}$ vs $H_a : H_0 \text{ false}$ using the Q test previously discussed was also undertaken. In this case, $Q = 15.47$ with 3 degrees of freedom which is highly significant (i.e. $p < 0.01$). We can reject the hypothesis that the proportions choosing the “consequence maximisation” consistent choice are the same for four conditions summarised in table 3.4.

²⁰ Mean and confidence intervals are for responses that correlate with a consequentialist approach are coded as 0 - alternatives are coded 1.

TABLE 3.5
THE IMPORTANCE OF RESPONSIBILITY AND CAUSE.

Question number, condition and cause	Mean ²¹	95% C.I.'s		Relevant		Not relevant		Don't know	
		N	%	N	%	N	%	N	%
Q.6 HIV/AIDS: Illegal drugs vs. blood transfusions	0.60	0.51-0.68	78	54	53	37	13	9	
Q.7 Lung cancer: Smokers vs. non- smokers	0.47	0.38-0.56	64	44	72	50	8	6	
Q.8 Mountain rescue: insurance vs. no insurance	0.85	0.78-0.91	116	81	20	14	7	5	
Q.9 General disease: Risky lifestyle vs. caution	0.40	0.32-0.49	52	37	77	54	13	9	
QALY max. Anti-QALY max. Equal									
Q.10 Life expectancy: socio-economic group	1	1	0	0	12	8	130	92	
Q.11 Life expectancy: lifestyle	0.92	0.87-0.96	11	8	6	4	127	88	

Notes

- As before, $H_o : p_{HIV} = p_{LC} = \dots = p_{RL}$ vs $H_a : H_o$ false was tested, where subscripts HIV, LC, RL denote ‘HIV/AIDS’, ‘Lung Cancer’ and ‘Risky Lifestyle’, respectively. In this case, $Q = 67.40$ with 3 degrees of freedom which is highly significant (i.e. $p < 0.01$).
- $H_o : p_{SEG} = p_L$ vs $H_a : H_o$ false was tested, where subscripts SEG and L denote ‘Socio-economic Group’ and ‘Lifestyle’ respectively. For related pairs of responses the McNemar test is used and the sample size is sufficiently large to justify using a chi-square approximation. The value of the test statistic is 9.09 allowing for a continuity correction and carries 1 degree of freedom. The null is rejected at the significance level, $p = 0.01$.

²¹ Means and confidence intervals are calculated on the basis of health maximisation (i.e. cause is not relevant) = 0, alternatives = 1.

MAJORITY VS. EXPERT OPINION AND POLITICAL AFFILIATION.

<i>Q 13. Response options</i>	Conservative	Labour	Liberal Democrat	Other
Popular Opinion (provide treatment)	6	46	1	0
Expert Opinion (do not provide treatment)	8	19	11	1
Don't Know	2	17	3	0

TABLE 3.7
VOTER OPINION

Question number and type of consultation	Mean ₂₂	95% C.I.'s		Strongly agree		Agree		Neutral		Disagree		Strongly disagree	
		N	%	N	%	N	%	N	%	N	%	N	%
Q.14 General Public Consultation Exercises	2.44	2.27-2.61	25	7	58	40	38	26	16	11	6	4	
Q.15 Surveys of Voters	2.49	2.31-2.66	26	18	55	38	37	26	19	13	7	5	
Q.16 Mirror private system	3.33	3.12-3.50	6	4	27	19	41	28	52	36	17	12	

Note

1. $H_0 : p_{CE} = p_{SV} = p_{PIM}$ vs $H_a : H_0$ false was tested, where subscripts CE, SV and PIM denote ‘Consultation exercises’, ‘surveys of voters’ and ‘ Private Insurance Mirror’ respectively. In this case, as the underlying response measure is ordinal (strongly agree to strongly disagree), the Friedman two-way analysis for k related samples was used. The test statistic has an approximate chi-squared distribution when the number of either observations and/or treatments is large which is the case as $n=142$ (allowing for incomplete observations which had to be removed for the analysis). The value of the test statistic, F , with 2 degrees of freedom is 46.82 which is highly significant (i.e. at $p < 0.01$).

²² Means and confidence intervals are based on strongly agree = 1,..., strongly disagree = 5.

TABLE 3.8
VOTING AND RIGHTS.

<i>Question number and description</i>	<i>Mean</i>	<i>95% C.I.s</i>		<i>Health max.</i>		<i>Public opinion</i>		<i>Don't know</i>	
				<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
Q.12 Treatment for Minority Population (Health max) vs. no treatment (Public Opinion)	0.13	0.08-0.20		112	78	17	12	15	10
Q.13 Provide Popular Treatment (Public Opinion) vs. expert opinion (Health Max)	0.59	0.49-0.68		48	33	69	48	27	19

Note

$H_o : p_{MP} = p_{PT}$ vs $H_a : H_o$ false was tested using the McNemar test for related pairs, where subscripts MP and PT denote ‘Minority Population’ and ‘Popular Treatment’ respectively. The value of the test statistic is 46.15 allowing for a continuity correction and carries 1 degree of freedom. The null is rejected at the significance level, $p = 0.01$.

Figure 3.2 a

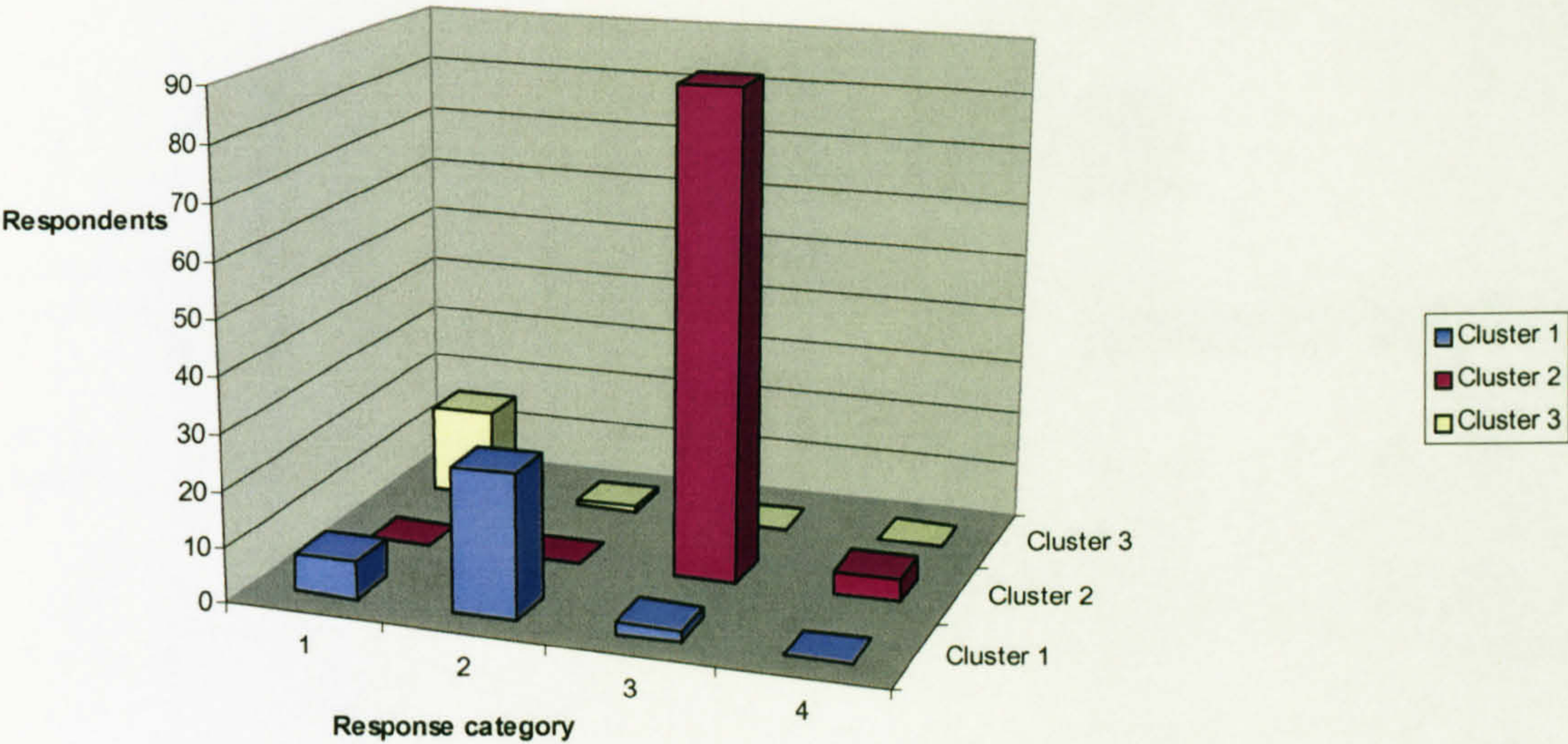


Figure 3.2 b

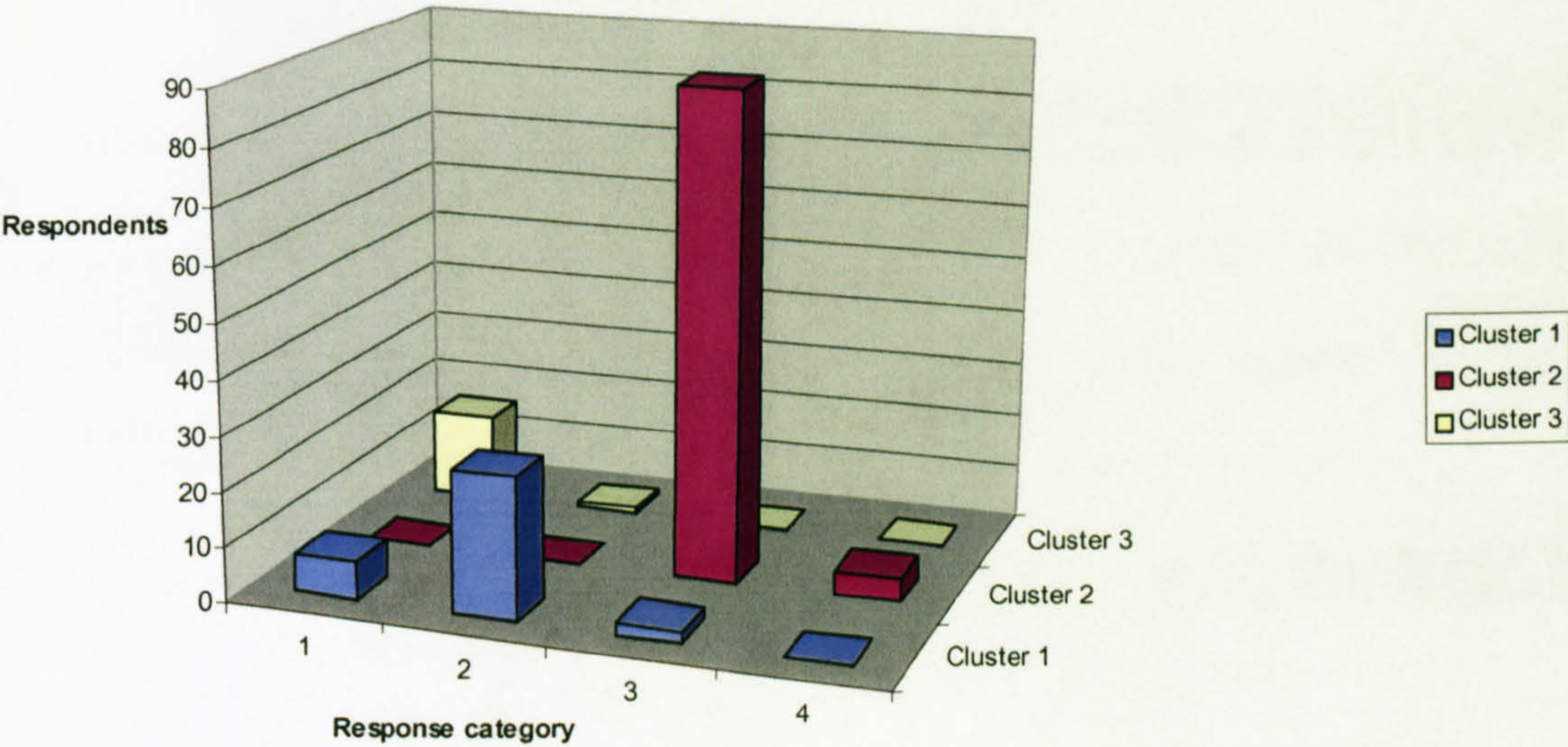


Figure 3.2 c

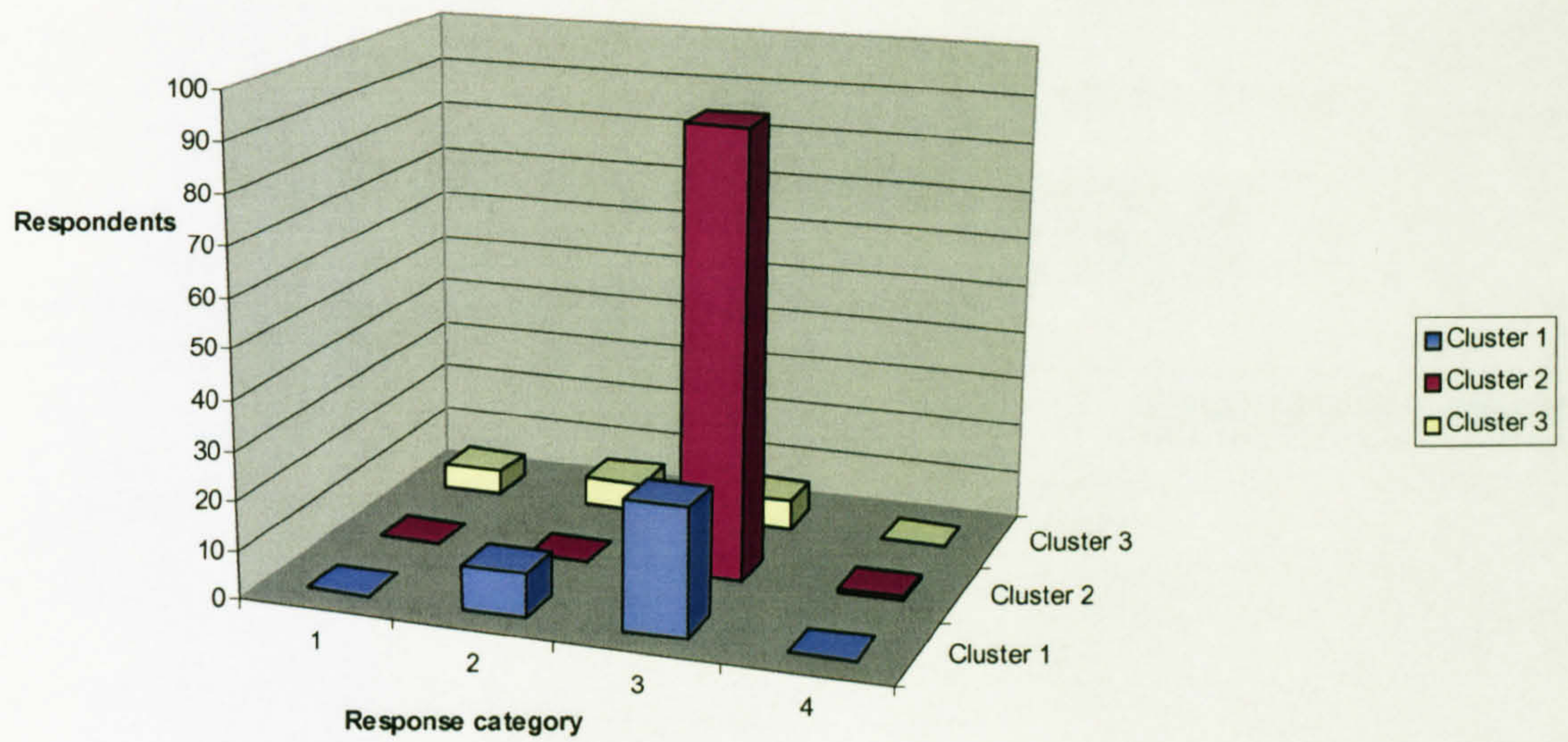


Figure 3.2 d

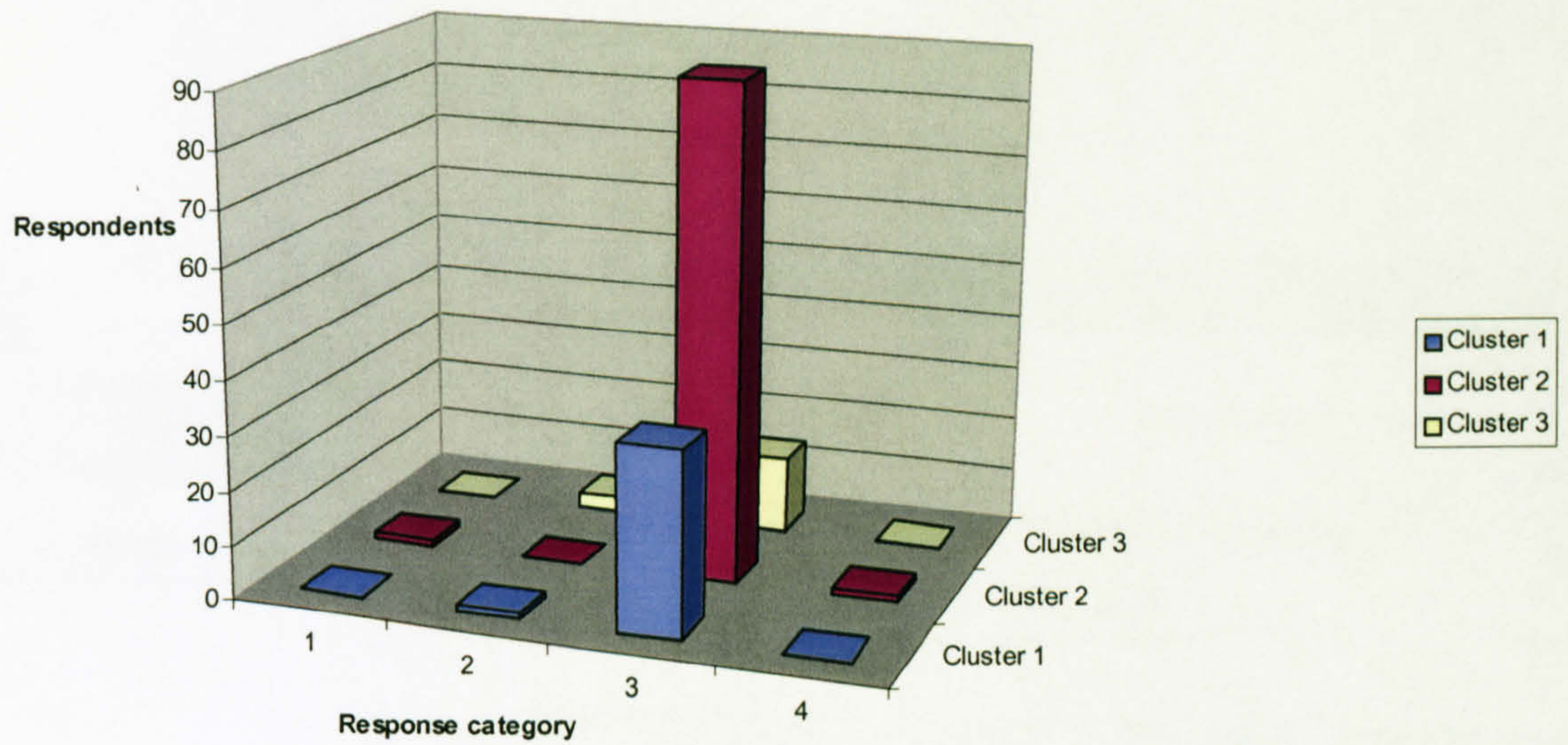
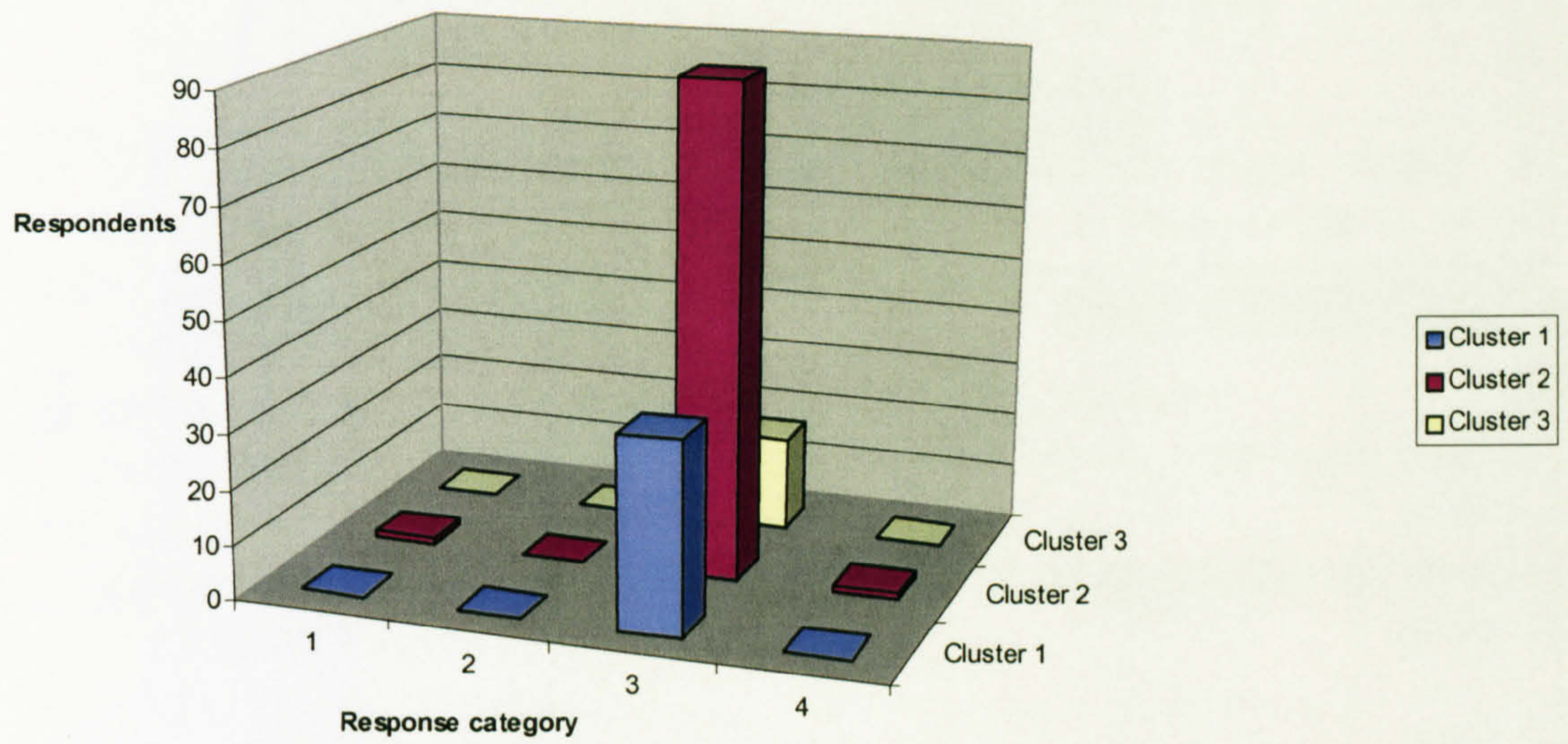


Figure 3.2 e



Appendix 3.1 Survey Instrument

HEALTH SURVEY

The UK National Health Service does not receive enough money to provide all the health-care that patients would like. This results in some patients having to wait longer than others to receive treatment. Some types of treatment are not provided at all.

This means that some patients are given priority over others.

The questions in this survey are designed to find out on what basis priority should be given.

It is not concerned with whether you think the National Health Service should get more or less money.

All replies will be treated as confidential.

The form should take no longer than about ten minutes to complete.

Please return the questionnaire in the enclosed envelope. No stamp is needed.

For each question please tick one box only, like this ☒.

It is important for our analysis that you respond to all questions. Thank you very much for your help.

Question 1.

If it were necessary to make a choice between treating one patient or another, do you think that it is acceptable to give priority to a person who has children, if the patients were similar in all other respects?

- ☐ Priority should be given to people with children.
- ☐ Priority should be given to people with no children.
- ☐ Each patient should have the same chance of receiving the treatment.
- ☐ Don't know.

Question 2.

If it were necessary to make a choice between treating one patient or another, do you think that it is acceptable to give priority to a person who is married over someone who is not married?

- ☐ A married person should be given priority.
- ☐ A non-married person should be given priority
- ☐ Each patient should have an equal chance of receiving the treatment.
- ☐ Don't know.

Question 3.

A disease effects two groups of people making them unable to work. One group consists of high wage earners. The other group are low wage earners. If it were not possible to treat all patients immediately, do you think that these wages should be taken into account?

- ☐ Priority should be given to the high wage group.
- ☐ Priority should be given to the low wage group.
- ☐ Patients from each group should have the same chance of receiving treatment immediately.
- ☐ Don't know

Question 4.

Imagine a situation where there are two patients suffering from a similar condition. The patients are the same sex, age, and both are single. In such a case, do you think it is acceptable to decide which one gets priority based on an assessment of how much pleasure each person gets from living?

- ☐ The pleasure a person gets from life should be taken into account
- ☐ The pleasure a person gets from life should not be taken into account
- ☐ Don't know

Question 5.

In each of the following scenarios you are asked to consider how funds should be allocated between two kinds of diseases. When doctors treat a person with either disease they can be expected to make a perfect recovery and have an average life expectancy. However, if left untreated, patients die quickly. The patients affected by each disease are similar with the exception of the age differences that are described in each of the particular scenarios below.

5i.

Disease A strikes members of one group when they are 40 years old while disease B strikes members of another group when they are 80 years old. How should funds be allocated?

- ☐ Funds should be used to treat all those effected by disease A (40 year olds) first. Only if there are funds left over should disease B (80 year olds) be treated.
- ☐ The funds should be used to treat more of those effected by disease A than disease B.
- ☐ Funds should be allocated equally between both diseases.
- ☐ Don't know

5ii.

Disease A strikes members of one group when they are 40 years old while disease C strikes members of another group when they are 70 years old. How should funds be allocated?

- ☐ Funds should be used to treat all those effected by disease A (40 year olds) first. Only if there are funds left over should disease C (70 year olds) be treated.
- ☐ The funds should be used to treat more of those effected by disease A than disease C.
- ☐ Funds should be allocated equally between both diseases.
- ☐ Don't know

5iii.

Disease A strikes members of one group when they are 40 years old while disease D strikes members of another group when they are 60 years old. How should funds be allocated?

- ☐ Funds should be used to treat all those effected by disease A (40 year olds) first. Only if there are funds left over should disease D (60 year olds) be treated.
- ☐ The funds should be used to treat more of those effected by disease A than disease D.
- ☐ Funds should be allocated equally between both diseases.
- ☐ Don't know

5iv.

Disease A strikes members of one group when they are 40 years old while disease E strikes members of another group when they are 50 years old. How should funds be allocated?

- ☐ Funds should be used to treat all those effected by disease A (40 year olds) first. Only if there are funds left over should disease E (50 year olds) be treated.
- ☐ The funds should be used to treat more of those effected by disease A than disease E.
- ☐ Funds should be allocated equally between both diseases.
- ☐ Don't know

5v.

Disease A strikes members of one group when they are 40 years old while disease F strikes members of another group when they are 41 years old. How should funds be allocated?

- ☐ Funds should be used to treat all those effected by disease A (40 year olds) first. Only if there are funds left over should disease F (41 year olds) be treated.
- ☐ The funds should be used to treat more of those effected by disease A than disease F.
- ☐ Funds should be allocated equally between both diseases.
- ☐ Don't know

Question 6.

Do you believe that those who contract HIV through injecting illegal drugs should be a lower priority for treatment than those who contracted the disease through being given contaminated blood transfusions?

- ☐ Those who contract HIV through injecting illegal drugs should be a lower priority than those who contract HIV through blood transfusions.
- ☐ Those who contract HIV via illegal drug use should be given the same access to treatment as those who contract HIV via contaminated blood products.
- ☐ Don't know

Question 7.

Do you believe that smokers who contract lung cancer should be given the same access to expensive treatment as non-smokers who contract lung-cancer?

- ☐ Smokers who contract lung cancer should be given the same access to expensive treatment as non smokers
- ☐ Non smokers should be given a higher priority for treatment of lung cancer than smokers.
- ☐ Don't know

Question 8.

Do you believe that mountain climbers should be required to take out an insurance policy to pay for any rescue services that they might require in the event of an accident?

- ☐ Mountain climbers should be required to take out insurance policies to pay for any rescue services
- ☐ Mountain climbers should not be required to take out insurance policies to pay for any rescue services
- ☐ Don't know

Question 9.

Do you believe that people who require medical treatment as a result of risky behaviour should be given a lower priority for treatment compared with patients who suffer from events beyond their control?

- ☐ Knowing risk-takers should be given a lower priority when determining access to health-care treatment.
- ☐ Knowing risk-takers should be given the same priority as non risk takers when determining access to health-care treatment.
- ☐ Don't know

Question 10.

Imagine a situation in which a disease effects two groups of people. Both groups are effected when they are 65 years old. Members of group A come from poor backgrounds and only have a life expectancy of 70 years whereas members of group B come from a wealthy background and have a life expectancy of 85 years. (On average, wealthy people live longer than the less well off). Which group should receive priority?

- ☐ The wealthy group with the higher life expectancy should have the highest priority for treatment.
- ☐ The less well-off group with the lower life expectancy should have the highest priority for treatment
- ☐ People from both groups should an equal chance of receiving treatment.
- ☐ Don't know

Question 11.

Imagine a situation in which a disease effects two groups of people. Both groups are effected when they are 65 years old. Members of group B, who have led healthy lifestyles, have a life expectancy of 85 years. Members of group A have taken risks with their health and only have a life expectancy of 70 years. Which group should receive priority?

- ☐ The group with the higher life expectancy should have the highest priority for health-care treatment.
- ☐ The group with the lower life expectancy should have the highest priority for health-care treatment.
- ☐ People from both groups should have an equal chance of receiving treatment.
- ☐ Don't know

Question 12.

It is shown that only members of a particular ethnic group are at risk from a particular disease. In a vote on health-care priorities this condition does not score highly because there are not very many members of this ethnic group in the area. Should treatment for this condition be a high priority?

- ☐ The health authority should give this disease a low priority.
- ☐ The health authority should not be influenced by the vote.
- ☐ Don't know.

Question 13.

If a health authority conducts a poll which shows that the majority of people think that a particular treatment should be provided, but doctors argue that it is rarely successful and should not be provided, what do you think should happen?

- ☐ The treatment should be provided.
- ☐ The treatment should not be provided.
- ☐ Don't know

Question 14.

Some people argue that health authorities should conduct consultation exercises (public meetings, asking groups made up from the public) to determine which health-care treatments are provided for patients in their areas. Do you agree?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree

Question 15.

Some people argue that health authorities should conduct surveys of voters to determine which health-care treatments are provided for the patients in their areas. Do you agree?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree

Question 16.

Some people argue that health authorities should try to base the provision of health services on the services people would buy if they had to take out private health-care insurance. Do you agree?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly Disagree

The following questions are to find out some information about yourself. This helps us to check that we have asked a variety of people. We would be very grateful if you could answer these questions.

Question 17.

How old are you?

- ☐ under 18yrs
- ☐ 18- 25yrs
- ☐ 26-45yrs
- ☐ 46-64 yrs
- ☐ 65+ yrs

Question 18.

Sex

- ☐ Male
- ☐ Female

Question 19.

Occupation

- ☐ Employed. If employed, what is the title of your job? _____
- ☐ Self employed
- ☐ Unemployed
- ☐ Retired
- ☐ Other (please specify) _____

Question 20.

What is your household income? Include here the income of yourself and anyone else that you live with before tax is paid.

- ☐ Below £5000 per year
- ☐ Between £5000 and £16000 per year
- ☐ Between £16000 and £25000 per year
- ☐ More than £25000 per year

Question 21.

Did you vote in the last election?

- ☐ Yes
- ☐ No

Question 22.

If you did vote, which party did you vote for?

- ☐ Conservative
- ☐ Labour
- ☐ Liberal Democrat
- ☐ Other

Please use this space for any comments you would like to make:

Thank you for completing this questionnaire. Please return it in the envelope provided - no stamp is required.

CHAPTER FOUR: PROCEDURAL PREFERENCES IN HEALTH-CARE

4.1 INTRODUCTION

Recent debate in the health economics literature on the normative foundations of economic evaluation has been conducted almost exclusively in consequentialist terms. It has been dominated by concerns for identifying appropriate outcomes and distributions of those outcomes. However, evidence presented in the previous chapter suggests that this debate may be missing the point; many of the observed objections to health maximisation are applicable to consequentialism in general.

One distinct branch of non-consequentialism that was touched upon in the previous chapter but has rarely been addressed by welfare economists is the concept of procedural preference; individuals may have concerns for the methods by which decisions are made in addition to the consequences of those decisions, Frey and Stutzer (2002). Some overlap can be seen here with “process utility”, an area of growing interest amongst health economists, see for example Donaldson and Shackley (1997). “Process utility” refers to the utility derived by patients from the process of medical care, as opposed to the impact on health outcomes or wider utilities. Ryan (1999), for example, included valuations of “attitudes of staff” and “continuity of contact with staff” in a conjoint analysis of in vitro fertilisation (IVF). “Process” is therefore used in a medical rather than philosophical sense. Furthermore, the issue is centred at the level of the individual patient as opposed to the societal level of decision-making that is the central concern of this thesis.

This chapter develops the concept of procedural preference as one branch of non-consequentialism relevant to health-care rationing. In section 4.2, a theoretical justification for the inclusion of such considerations in economic decision-making is given. It is argued that those who hold preferences for procedures may do so for rational and non-instrumental reasons. Section 4.3 reviews a number of studies which have contributed to our understanding of this branch of non-consequentialism. The bulk of this literature comes from Social Psychology and legal studies and forms the basis of a taxonomy of procedural characteristics. This taxonomy was then used to develop a survey instrument, discussed in section 4.4, which aimed to establish the relevance of each procedural characteristic in the context of health-care rationing. Results are presented in section 4.5. Section 4.6 concludes.

4.2 THE THEORETICAL BASIS FOR PROCEDURAL PREFERENCES.

Non-consequentialists need not commit to the viewpoint that outcomes are unimportant, just that they are not the *sole* determinant of social welfare. The position is one which mirrors the author's view of procedures: clearly individuals have preferences for particular types of procedures because they expect better outcomes to arise as a result but there are convincing reasons to believe that the values procedures generate are not restricted to this instrumental role. Traditionally, welfare economists' interests have not extended beyond this instrumental dimension and they have dismissed as irrational any apparent preferences which cannot be explained in this manner. As Suzumura (2000) notes, this view reflects Rawls's concept of *perfect procedural justice*¹ whereby the benefits of procedures are assessed by reference to an outcome morality. In a discussion restricted to fairness, it is argued that fair procedures are those which never fail to bring about fair outcomes. Interestingly, Ng (1988, p.217) specifically excludes such

¹ See Rawls (1971).

instrumental values from his definition of procedural preferences, mirroring Rawls's concept of *pure procedural justice*, and the same definitions are used here (although no attempt is made at quantifying the magnitude of the two effects in the empirical section). According to Ng (1998, p218):

“...if people prefer one-person-one-vote, the use of this method directly yields utility. This is a fact that cannot be ignored. Even if the use of an alternative method is more efficient in terms of securing a better outcome, it has to be better than the outcome under one-person-one-vote by a sufficiently big margin to offset the direct preference for one-person-one-vote for it to be desirable overall.”

Arrow (1951) too acknowledged the inherent values of procedures:

“[A]mong the variables which taken together define the social state, one is the very process by which the society makes its choice. This is especially important if the mechanism of choice itself has a value to the individuals in the society. For example, an individual may have a positive preference for achieving a given distribution through the free market mechanism over achieving the same distribution through rationing by the government. If the decision process is interpreted broadly to include the whole socio-psychological climate in which social decisions are made, the reality and importance of such preferences, as opposed to preferences about the distribution of goods, are obvious.” (Arrow, 1951, pp.89-91, quoted in Suzumura, 2000, p.21).

The problem with utilitarian, welfare economics is that the domain over which preferences are allowed to exist is excessively narrow to deal with concerns of this type and therefore its policy prescriptions will be sub-optimal. This section suggests reasons why procedures may generate inherent values in addition to this instrumental role, corresponding to what Rawls referred to as pure procedural justice.

For some procedures the distinction between inherent and instrumental value can be nebulous. Many social and economic procedures *may* have an historical and instrumental basis but for some procedural characteristics this link may now have become distilled to the point that the instrumental view no longer provides a useful explanation of why they are valued. Indeed, Ng (1988) asserts that non-instrumental procedural preferences exist *mainly* because of tradition and cultural influences. Sugden (1986) too gives the example of “custom and practice” in settling labour disputes in his discussion of natural law. The contention here is that many procedures may have an inherent, rather than instrumental value because they have become societal rules or conventions although their origin may indeed be instrumental.

Much of the research in this field has been cast in terms of concerns for procedural justice or fairness. The term preferences is used here, following Ng(1988), to emphasise the position that procedures may be of legitimate concern in the same way as outcome based concerns. However, concerns for fairness and equity are likely to be the motivation for a significant proportion of procedural preferences in exactly the same way that such concerns motivate many concerns for the distribution of outcomes , particularly when individuals are responding from the viewpoint of a citizen where a publicly funded health system exists. As Okun (1975) accurately notes:

“the state is not something which should be turned into a vending machine.”

Furthermore, there are parallels between situations where conflict exists, which is the focus of much of existing research into procedural preferences, see for example Thibaut and Walker (1975), and health-care rationing, particularly in publicly funded systems. Where opposing parties have interests in outcomes which are diametrically opposed, the opportunities for a solution defined solely in terms of consequences may be impossible. Conflict resolution may therefore only be achievable by reference to procedural criteria since parties may accept unfavourable outcomes if they are the result of some mutually acceptable procedure which was agreed *ex ante*. Those concerned only with procedural fairness would accept any outcome provided that the procedures which brought it about are considered fair. In this sense, justice might lexicographically dominate preferential concerns.

Health-care rationing exhibits many of these same characteristics. The essence of the rationing problem is that not all needs can be met and individuals are not operating from behind a (thick) veil of ignorance. Therefore, when defined purely in terms of substantive entitlements to health-care treatments individual preferences are not easily reconciled. In this situation, establishing substantive entitlements will inevitably contravene the preferences of some and this may help explain the difficulties that have been encountered in trying to establish distributive rights, see for example Lenaghan (1997) who argues that in the light of these difficulties in the UK and other countries, the focus should be on procedural health-care rights.

An interesting contribution on this theme comes from Krehbiel and Cropanzano (2000). They outline a psychological, cognitive model of emotional responses which suggests that there are two stages of individual appraisal. The first of these is primarily a

judgement based on an assessment of outcomes which can trigger particular emotional responses. Procedural judgements take place as part of the secondary appraisal where different emotions can be triggered. For example, if an unfavourable outcome is paired with an unfair procedure then anger, guilt, frustration and anxiety are likely to occur. Under this model the importance of procedural issues in the context of health-care rationing occurs because, when operating from behind a (thin) veil of ignorance, any distribution is considered unfavourable; particularly if the concept of opportunity cost is not readily accepted.

Procedures also have an inherent value in situations where the causes of outcomes are uncertain. In such situations it is only by reference to procedures that behaviour can be judged and appropriate action taken. If poor outcomes are observed, the desire for fair accountability requires reference to the procedures responsible for generating the outcome. Additionally, mechanisms must be in place which allow action against the responsible party to be taken.

The procedures which lead up to distribution of outcomes are complex in terms of the degree, type and duration of social interactions they entail. Consequentialism has nothing to say about these social interactions. In the context of public policy decisions, these social interactions take place between government decision-making bodies and either individuals or community groups where there is a clear difference in the degree of power between parties. The procedures used to determine distributions can therefore convey a substantial degree of information about the way decision-making bodies perceive those subject to the results of its choices, for example how important they think it is to reach a “right” decision, the importance of the viewpoint of those affected, how

choices are presented and the type of information revealed or used in the decision-making process.

4.3 EXISTING LITERATURE

Increasingly there is evidence to support the existence of preferences for procedures, beyond those which are merely instrumental. Social Psychological research can be traced back to Thibaut and Walker's seminal work (1975,1978). Whilst this work focussed on the legal field and provided many examples of (mainly) experimental evidence pertaining to this setting, it also provided the first general conceptual and theoretical ideas relating to procedures. A limited body of empirical work generally relating to tightly defined legal scenarios did exist prior to Thibaut and Walker's work, for example Kalven and Zeisel (1966), Rosenberg (1964), and numerous studies have investigated the phenomenon since that time, for example Lind *et al.* (1990). Much of the early empirical work in the field applied procedural justice considerations to the legal field where it was shown not only that such considerations were important to individuals but that often they were perceived to actually outweigh concerns for outcomes, for example Tyler (1984, 1987a). Leventhal (1980) provided a theoretical basis for procedural concerns in non-legal contexts which prompted numerous empirical investigations, for example Tyler *et al.* (1985) investigated political procedures, Lissak *et al.* (1983) studied the determinants of job satisfaction, and Greenberg and Folger (1983) furthered work relating to organisations. The appropriateness of procedural considerations in economic decision-making has also been the subject of a small amount of research: Bies *et al.* (1993) replicated a study by Kahneman *et al.* (1986) and established that perceptions of fairness regarding market activities were influenced by procedural factors, a finding confirmed in a similar study by Frey and Pommerehne (1993). Anand (2001) provides evidence of procedural sensitivity in a range of

economic and social choice problems amongst UK voters. Other studies conducted by a number of Swiss economists have examined preferences for decision-making mechanisms, Oberholzer-Gee *et al.* (1995), Pommerehne *et al.* (1997), and found varying levels of support for decisions concerning the siting of nuclear or toxic waste facilities dependent on the process by which the decision was reached.

A number of commentators have identified the various dimensions of procedures which, it is claimed, give rise to these preferences. The main contributions to this literature are from Lind and Tyler (1988) and Levanthal (1980), although certain other dimensions or details have been added from other sources. These dimensions of procedures are outlined below. It is apparent that whilst significant differences exist between authors it is also the case that the categories suggested are not incompatible.

4.3.1 Voice

The most consistent finding in all research into procedural preferences is that individuals value involvement in decision-making processes, whether direct or through representatives, and is one of the few areas researched by health economists, Coast (2001). Clearly an element of this importance is instrumental yet the intrinsic value of involvement is also a consistent finding and is referred to as the “value expressive perspective on voice” by Tyler (1987b). Anand (2001) distinguishes between micro and macro elements of voice, with the latter version referring to cases where representation rather than direct voice is the feasible option.

The value expressive perspective exists because voice is a means by which decision-makers can convey a degree of respect to those to whom the decision will apply². An

² Voice can be seen as a “dignity good” according to Lane (1988), quoted in Lind *et al.* (1990).

individual prefers to be accorded voice in a decision-making procedure because it implies that their opinion is worth hearing, irrespective of the effect that voice might have on consequences.

4.3.2 Consistency

Procedural consistency, applied both inter-temporally and inter-regionally, reflects one of the most salient concerns of popular and political debate. Leventhal¹⁶ outlines the close relationship between this dimension of process and the notion of equality of opportunity. Violation of consistency is an indication that procedural fairness is being violated, giving potential favour to some recipients of health-care. Indeed, one of the most common criticisms of current, implicit rationing practices is the resultant “postcode prescribing”. The procedural view is that such inconsistencies may be unacceptable because they reflect inconsistencies in decision-making methods and that variations in entitlements would be more acceptable if they could be shown to be the result of unvarying procedures.

4.3.3 Absence of vested interests

In many decision-making contexts there is an unequal balance of power between decision-makers and those who may be affected by the decision and this is particularly true in the context of health-care rationing irrespective of the level at which this takes place. Preferences for procedures which inhibit the extent to which biases can manifest themselves do so because of concerns about the fairness of decision-making methods.

4.3.4 Correctability

Decision-making procedures will be more acceptable if there are mechanisms which allow decisions to be challenged and reversed if required. This condition arises because

individuals recognise that there is always a potential for “incorrect” decisions to be made, either in terms of the procedure or the outcome. This condition is therefore strongly allied to the requirement for transparency which assists the identification of such mistakes.

The methods by which such appeals may operate are likely to be highly situation specific. For example, where outcomes have been allocated and are not reversible, appeals procedures may be limited in value other than ascribing blame or punishment. In these situations, appeals procedures may be of greater value as a means of correcting identified flaws in decision-making process prior to the decision being made. The instrumental value of allowing opportunities for appeals to be made may therefore be related to outcomes or other procedures. Furthermore, decision-making mechanisms which have clear means by which challenges and reversals of “incorrect” decisions can be made can convey a sense of confidence in the process as a whole, particularly if such reversals would be time consuming and/or expensive.

4.3.5 Accuracy

Efficient evaluation of competing options requires accurate information such that the costs and benefits of each option can be assessed. Procedures which provide mechanisms for basing decisions on accurate information are therefore preferred for instrumental reasons. However, acquiring accurate information is not a costless exercise itself and consequentialists would only recommend that such information is pursued up to the point where marginal benefit equates its marginal cost. If an inherent, procedural value exists in excess of this instrumental value then it becomes desirable to pursue accurate information beyond this level. Such an inherent value may particularly arise

because the collection and use of accurate information conveys the extent to which decision-makers feel a particular issue is of importance.

4.3.6 Transparency

Whilst individuals might value the ability to contribute opinions in the decision-making process either directly themselves or through their representatives, communication flows in the reverse direction are also important. In the context of government decision-making, procedures are more popular if a rationale is provided by the decision-maker. For example, Daniels and Sabin (1997) suggest that procedural fairness “requires openness or publicity, that is, transparency about reasons for a decision.” (p.323).

The provision of a public rationale is a procedural tool which serves to guarantee the legitimacy of the process and to allow judgements regarding fairness to be made; transparency is a means by which the violation of other procedural rules can be detected and may therefore increase the level of confidence the public has in government decisions.

These six dimensions of procedures do not constitute an exhaustive list but those for which there are clear links to Rawls’ conception of pure procedural justice. Instrumental values are likely to exist in conjunction with any inherent value for each of these dimensions; the viewpoint taken here is not that concerns for consequences do not matter but that they are not sufficient in themselves as a basis for social choice decisions. In the empirical work which follows it is useful to reiterate the author’s view that the purpose of identifying procedural preferences is to contribute to a pluralistic framework which embodies these preferences alongside consequences, rights and duties, *inter alia*.

4.4 PROCEDURAL PREFERENCES IN THE CONTEXT OF HEALTH-CARE RATIONING: SURVEY METHODS

A self-administered postal questionnaire was sent to a total of 412 individuals in the Milton Keynes district. The names were drawn at random from a sampling frame which consisted of the electoral register for four electoral wards. These wards were selected on the basis that they contained a variety of socio-economic groups³. Of these 31 were returned on the basis that the individual no longer lived at the address and a total of 118 were returned. This gave a response rate of 31%.

It was recognised at the preliminary design stage that responses to surveys of this type are extremely sensitive to design. It was therefore essential that potential problems commonly discussed in the survey literature were addressed, Dillon (1990). In conjunction with discussions with colleagues, two pilot studies were undertaken where respondents were encouraged to give comments on survey design in addition to answering the questions. Framing issues, ordering and response rates were the most prominent issues to be addressed at these planning stages. The final form of the survey with covering letter is shown in Appendices 4.2 and 4.3. To minimise responder bias, questions were randomly framed in a positive manner in some sections and negatively in others. Socio-economic details were gathered on a limited number of characteristics in order to maintain acceptable response rates.

The survey was designed to examine the relevance of each of the dimensions of procedures mentioned above and to position these empirical values against an anchor which reflects concerns for consequences. Each section of the survey gave a brief,

³ This was on the generous advice of June Allen of Milton Keynes Council.

neutral, definition of the meaning of the procedural dimension it was designed to test in order to simplify and clarify some potentially ambiguous or confusing terms. Respondents were asked to indicate on a five point Likert scale the extent to which they find these dimensions of procedures important in each of three scenarios where health-care rationing decisions are made; the individual clinician, health authority and governmental levels. An additional section was included which asked about the importance of consequences. The Likert scale was selected as the most appropriate method of generating data that allows us to identify the validity of procedures and to judge these empirical results relative to those generated in the same manner which reflect concerns for consequences. Alternative designs, such as conjoint analysis, are capable of quantifying potential trade-offs both between procedures and consequences or between individual procedures. Such designs, whilst generally favoured by economists since they require respondents to make choices, are significantly more complex and were not considered appropriate at this time.

4.5 HEALTH-CARE RATIONING SURVEY: RESULTS

4.5.1 Characteristics of the sample.

Table 4.1 presents the salient socio-economic characteristics of the sample and provides national estimates on those same dimensions as a means of identifying any potential bias on these general dimensions. The sampling frame is not a random selection of the general population and the decision to respond to the survey could not be controlled.

Comparisons are made by reference to data from the 1991 census and from the General Household Questionnaire (GHQ). 95% confidence intervals are shown throughout. The prominent feature of this analysis is that, despite the small numbers of respondents, there are few traits which differ significantly from those observed in the general public.

A slightly greater number of females than males responded and, whilst, this difference was itself slightly greater than the proportions observed in those over 17yrs of age in the 1991 census, it was not a significant one. The average age of respondents is greater than Census data predicts. This difference is particularly prominent in the “twenties” age group, where less than 9% of the sample were located compared to 20% of the general public, and in the fifties and sixties age groups, which each had over 21% observed whereas less than 14% of the population falls into each band. These are the only observed differences which are statistically significant from the figures for the population although in several cases the population figures lie towards the bounds of the confidence intervals. The majority of respondents were in full-time paid work (54%) with the next largest category consisting of the retired (22%).

4.5.2 Primary results

Responses were coded on a scale of 1-5 indicating “strong agreement” to “strong disagreement” with the importance of each dimension of procedure tested. Table 4.2 shows the distribution of responses together with median, mean and 95% confidence intervals of the mean for each of the responses. Analysis of the mean is based on the assumption that the response scale is symmetrical about the neutral response category and has cardinal properties, that is the difference between each response category is seen as equal. The main interest is in identifying those situations where mean proportions, as indicated by the confidence intervals, equate to three signifying neutral attitudes. For each of the seven dimensions surveyed (six procedural) we also test $H_0: p_d = p_{ha} = p_g$ v. $H_a: H_0 \text{ false}$, using the Friedman two-way analysis for k -related samples, where d = doctors, ha = health authorities and g = government, Siegel and Castellan (1988). The test is appropriate since responses are on an ordinal scale and is

also used to test for differences between responses in each of the categories. These results are shown in table 4.3. The Wilcoxon matched-pairs signed-ranks test was used to test whether the differences in the distribution of responses given to procedural questions asked at different levels of decision-making were significantly different. The same statistical method was also used to test whether responses to each of the procedural questions differ significantly from those given in relation to consequences for the equivalent level of decision-making. These test results are shown in table 4.4.

Results indicate that for each of the six procedural dimensions tested, and in each of the three scenarios surveyed, the general public believe procedures are important. Mean proportions are all below three, although confidence intervals do not universally support the hypothesis that responses differ significantly from indifference (a score of three). The median response is in the “agree” category in all but one procedural scenario.

The importance of consistency in the procedures used in rationing decisions is of a similar magnitude in the scenarios based at the doctor and health authority levels (means are equal to 1.9 and 1.91 respectively). The mean score of 2.27 for this procedural dimension at the governmental level indicates a lower degree of importance. This is interesting in the light of the importance attached to distributive consistency, notable in media references to “postcode prescribing”, given that this is most relevant to the governmental decision-making level. If the importance of procedural consistency were purely instrumental, as a means of ensuring distributive consistency, we might expect to see a greater degree of importance recorded at this governmental level. Wilcoxon test statistics indicate that the observed difference between attitudes to consistency in decisions made at the government level and each of the doctor and health authority levels are statistically significant at the 5% level. The Friedman test statistic of

0.03, shown in table 4.3, confirms that the difference between the three sets of responses is statistically significant.

The second set of questions relate to the importance of avoiding vested interests when making rationing decisions. Health services are characterised by numerous stakeholder groups who are likely to have competing interests regarding health rationing decisions ranging from financial, as in the case of pharmaceutical companies, to the protection of personal interests as may be the case for some doctors, in addition to those of potential patients and their families. Whilst sample means indicate a general agreement with the importance of excluding such interests from the decision-making process (all are less than three) only in the case of doctors is this a significant difference. Friedman and Wilcoxon test results confirm this result.

The importance of reversibility is tested in the third section. Responses provide additional support to the hypothesis that different criteria are applied to priority setting decision-making when made at the doctor level compared to macro level decisions. Table 4.3 shows that responses within this section are significantly different whilst table 4.4 shows that these differences do not exist between responses relating to Health Authority and Government decision-making. Confidence intervals indicate that mean responses are approximately neutral in the context of doctors rationing decisions, whilst there is slight support for Health Authorities and Governments decisions to be reversible in the face of protests (means of 2.6 and 2.5 respectively).

Greater support is shown for using accurate information in decision-making at all levels with mean proportions equal to 1.7, 1.8 and 1.9 for doctors', health authorities' and governmental priority setting decision-making. In no case does the upper bound of the

confidence interval approach three. Only the difference between doctors and governmental decision-making is a statistically significant one (5% level) as indicated by Wilcoxon test statistics. Using accurate information is a dimension of decision-making which has clear consequential as well as procedural implications which may account for the strength of support exhibited by respondents. The use of accurate information not only promotes efficient outcomes (however defined) but may be seen as a reflection of how important the decision and those likely to be affected by it, are to the decision maker and, in this situation, to society.

Support for transparency of decision-making is a further procedural dimension where respondents seemingly apply different criteria to doctors decision-making compared to health authorities and government. The latter two scenarios both have mean values of 1.6 and are not significantly different (Wilcoxon test score is 0.363) whilst a mean value of 1.9 in relation to doctors decision-making indicates a much lower level of agreement that doctors decisions should be open to scrutiny. Wilcoxon and Friedman tests indicate that this is a statistically significant difference.

Voice has been shown throughout previous research to be one of the most highly valued dimensions of process and is tested in section seven of this survey. Questions were framed in a general manner, making reference to various types of public consultation to avoid any bias respondents might feel towards particular mechanisms rather than the concept of public involvement *per se*⁴. Results in table 4.2 indicate only a moderate level of support for public involvement in decision-making and confidence intervals for all three scenarios cover a value of two which equates to “agree”. A Friedman test statistic of 0.11 supports the hypothesis that the responses to the three questions are not

⁴ The question asked was similar to that tested in chapter three in the context of Health authorities and yields similar results.

equal and pairwise tests shown in table 4.3 show that these significant differences exist between responses relating to government decision-making and each of the other two scenarios. Respondents feel that it is more important for governmental rationing decisions to be made in consultation with the public than for health authorities and doctors.

The final section of the survey asks respondents to indicate the degree to which they believe the consequences of health-care options are relevant in the same three rationing scenarios as in the questions relating to procedures. Means relating to these three scenarios are in excess of three (3.18, 3.03 and 3.04 for doctors, health authorities and governmental decision-making respectively) although these results are not statistically significantly different from neutrality. In each of the three decision-making scenarios confidence intervals include in their range values below three, the “agreement” domain of responses and the results are therefore somewhat ambiguous. Furthermore, it is not clear that responses to this set of questions is entirely consistent with responses given to previous questions. Whilst general support for the procedural concept of using accurate cost and benefit information was indicated, it appears that simultaneously respondents do not wish for this information to be taken into account. With this potential inconsistency in mind, it is worth reiterating that in none of the previous sections were means ≥ 3 . Both Friedman and Wilcoxon tests reveal that there is no significant difference between the three sets of responses.

Wilcoxon signed-rank tests were also used to examine the observed differences between responses in this final section with each dimension of procedure. Test results are shown in the final column of table 4.3. In eighteen situations a greater mean level of support for procedures compared to consequences was recorded. Sixteen of these differences

were found to be statistically significant. The two exceptions both occur within the second procedural category; respondents do not feel it is any more important for health authorities and governments to avoid consulting those who may have vested interests than it is to consider both costs and benefits.

4.5.3 Cluster Analysis

Cluster analysis is applied here to provide a statistical categorisation of relatively homogenous respondents. An agglomerative, hierarchical method was applied. This approach initially allocates each respondent to a separate cluster. In the subsequent step the two observations closest to each other are joined. Distance between clusters was measured by squared Euclidean distance⁵. The next stage either pairs together the next closest observations or adds another observation to the existing pair. The process continues until all observations form a single cluster. Data relating to this process is used to determine the appropriate number of clusters. Ward's (1963) clustering procedure combines clusters at each stage of the analysis in order to minimise the amount of information loss (defined in terms of an error sum-of-squares criterion) at each stage, Everitt (1993) and was used throughout.

The results of each of these steps is shown in Appendix 4.1. Appendix 4.2. shows the equivalent dendrogram, a graph which illustrates the fusions of clusters made at each stage of the analysis. The information contained in both appendices were used to judge the number of clusters appropriate for this data. Abrupt changes in measures of

⁵ The Euclidean distance measure is probably the most commonly used and is relevant here since all responses are measured on the same scale, Everitt (1993). However, for use with Ward's linkage method it is considered more appropriate to use the squared Euclidean distance to avoid standardisation problems. Formally, distance is:

$$d(i, k) = \sum_j (x_{ij} - x_{kj})^2 \text{ where } d(i, j) \text{ in row } i \text{ and column } j \text{ is the distance between observations } i \text{ and } j.$$

similarity and distance between clusters occur at a number of stages from step 99 onwards. The most prominent of these occur between stages 103 and 104 (similarity changes from -65.99 to -109.16 and distance changes from 368.51 to 464.34) which equates to three clusters. Examination of the dendrogram confirms the three cluster solution is appropriate and the results of re-running the clustering procedure based on this number of clusters appear logical, see table 4.5. To aid clarity, this cluster analysis is also presented graphically in Figure 4.1. This is a simplified representation that combined responses within each cluster across different levels of decision-making for each procedural dimension. Columns therefore represent the mean response across three questions for members of that cluster.

Cluster 1 consists of 31 (29%) respondents who exhibit the strongest aversion to the use of outcomes in health-care rationing decisions; they may be loosely categorised as an anti-consequentialist group. In general, respondents in this cluster agree that the consideration of procedural factors is important but the strength of this agreement is not strong in the main. Mean values for respondents in this category approximate to two (agreement) rather than one (strong agreement). The support for procedural dimensions of rationing decisions does not extend to the need to exclude the input of those with vested interests. The mean response in this category indicates that vested interests should not be excluded from rationing decisions. There is further evidence that this group considers the importance of procedural considerations to vary considerably across the three levels of decision-making surveyed, particularly between decisions made by doctors and the government. Differences are larger within this cluster than in either of the other two.

The largest group, cluster two (n=59, 56%) may be characterised as “proceduralists”. Although mean responses in this cluster indicate that respondents are mildly in favour of consequences being used to determine health-care entitlements, stronger support for procedural categories is evident. All procedural dimensions of decision-making receive reasonably strong levels of support as indicated by a large number of mean values falling between two, which corresponds to “agreement”, and one, which corresponds to “strong agreement”. Membership of this cluster is associated with the strongest mean level of support for the consistency and absence of vested interest dimensions of procedure. The reversibility of decisions in the face of protests is an exception to this with the mean responses from this group approximating to three, neutral.

Cluster three (n=16, 15%) are the most pluralistic group. They exhibit the strongest preferences of any of the clusters for the incorporation of consequences into health-care rationing decisions. However, this cluster also exhibit the strongest level of support for four of the six procedural dimensions: reversibility, accuracy of information used, transparency and voice. Interestingly, and in common with cluster one, there is evidence of disagreement with the need to exclude those with vested interests from contributing to the decision-making process. This level of disagreement is much stronger in cluster three.

4.5.4 Multinomial Logit Analysis

A regression analysis was undertaken in an attempt to identify correlations between cluster membership and a limited number of socio-economic details from respondents. Due to the categorical nature of both the dependent and independent variables a multinomial logit procedure was considered appropriate and results are shown in Table

4.6. Few of the characteristics were found to have a statistically significant impact⁶. The largest cluster, cluster 2, acts as the base. Full-time paid workers, the retired and housepersons were more likely to be members of cluster 1, the anti-consequentialist group. Those in the highest income band, over £30,000 per annum, and those in their thirties, were significantly less likely (at the 10% level) to be members of this cluster relative to cluster 2. None of the variables had a statistically significant impact on membership of cluster three.

4.6 CONCLUSION

In this chapter a specific area of non-consequentialism has been developed and applied to health-care rationing. The chapter argues that welfare economics should have much to say about how health-care distributions are achieved but in practice the issue has been sidestepped: such concerns are considered appropriate by consequentialists only to the extent that they may have instrumental value.

For those who responded to the survey, procedures matter. The extent of this importance varies according to the type of procedure and the decision-making context to which it is applied, but the way in which decisions regarding health-care rationing are made is important to individuals. The data suggest that these preferences are not merely a reflection of the instrumentality of procedures since lower levels of support are observed for rationing decisions which are based solely on an assessment of consequences. Legitimate reasons for holding pure procedural preferences have been suggested and the empirical data support these hypotheses. As revealed by the cluster analysis, for most respondents procedures *and* consequences are important. This

⁶ This analysis was performed using the STATA statistical package.

Chapter 4: Procedural Preferences in Health Care
provides further support for a pluralistic normative foundation for approaches to health-care rationing.

The failure of economists to address such issues in some ways mirrors the attitudes of clinicians forty years ago. Fox and Swazey (1974) examined in detail the procedural techniques used to allocate kidney transplants in the 1960's and found exactly the same consequentialist concern of clinicians in contrast to the procedural concerns of the public. One of the clinicians involved demonstrated this attitude when he stated that:

“[We] simply could not understand why everyone was much more interested in the existence and operation of the lay selection committee than in the fact that in two years we had taken a disease, end-stage kidney disease, and converted it from a one hundred percent fatal prognosis to a ninety-five per cent two year survival.”

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Table 4.1: Socio-economic characteristics of respondents

	MALE		FEMALE		TOTAL		COMPARATIVE	95% C.I.s
	N	(%)	N	(%)	N	(%)	STATISTICS ¹	
<i>Gender</i>								
Male	~	~	~	~	52	(44.8)	47.7	36-54
Female	~	~	~	~	64	(55.2)	52.3	46-64
No response	~	~	~	~	2	~	~	
<i>Age</i>								
20-29	4	(3.5)	6	(5.2)	10	(8.7)	20.0	4-15
30-39	10	(8.7)	11	(9.6)	21	(18.3)	18.0	12-27
40-49	9	(7.8)	8	(7.0)	17	(14.8)	17.4	9-23
50-59	9	(7.8)	16	(13.9)	25	(21.7)	13.7	15-30
60-69	14	(12.2)	11	(9.6)	25	(21.7)	13	15-30
70-79	3	(2.6)	9	(7.8)	12	(10.4)	9.5	6-18
80-89	2	(1.7)	3	(2.6)	5	(4.3)	4.3	1-10
Missing	1				3			
TOTAL	51	(44.8)	64	(55.2)	~	~	~	~
<i>Household Income</i>								
≤£10,000	6	5.8	14	13.5	20	(17.2)		
£10,001 - £15,000	7	6.7	8	7.7	15	(12.9)		
£15,001 - £20,000	5	4.8	6	5.8	11	(9.5)		
£20,001 - £30,000	11	10.6	14	13.5	25	(21.6)		
>£30,000	19	18.3	14	13.5	33	(28.4)		
Missing	4	(3.5)	8	(7.0)	14	(12.1)		
<i>Employment</i>								
In full-time education	0	(0)	3	(2.6)	3	(2.6)	4.3	0.5-7.5
In full-time paid work	39	(34.2)	22	(19.3)	61	(53.5)	45.1	44-63
Unemployed	2	(1.8)	0	(0)	2	(1.8)	5.6	0.2-6
Sick or disabled	1	(0.9)	3	(2.6)	4	(3.5)	3.8	1-9
Retired from work	9	(7.9)	16	(14.0)	25	(21.9)	19	15-31
Looking after the home	0	(0)	10	(8.8)	10	(8.8)		
Other	1	(0.9)	8	(7.0)	9	(7.9)	22.7	10-25
Missing	0		2		4			
	52		62					

¹ Gender, age and employment status are taken from the 1991 Census for England only.

Table 4.2: Procedural preferences

VARIABLE	STRONGLY AGREE				NEITHER AGREE NOR DISAGREE				STRONGLY DISAGREE		MEAN	95% CONFIDENCE INTERVAL	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)		Lower	Upper
Consistency													
Doctor	43	(36.4)	53	(44.9)	8	(6.8)	9	(7.6)	2	(1.7)	1.9043	1.7280	2.0807
Health Authority	40	(33.9)	57	(48.3)	6	(5.1)	9	(7.6)	2	(1.7)	1.9123	1.7385	2.086
Government	44	(37.3)	34	(28.8)	11	(9.3)	14	(11.9)	12	(10.2)	2.2696	2.0185	2.520
Vested Interests													
Doctor	34	(28.8)	40	(33.9)	5	(4.2)	26	(22.0)	9	(7.6)	2.4386	2.1905	2.6867
Health Authority	30	(25.4)	30	(25.4)	6	(5.1)	31	(26.3)	15	(12.7)	2.7411	2.4695	3.0126
Government	25	(21.2)	22	(18.6)	15	(12.7)	29	(24.6)	20	(16.9)	2.9730	2.7004	3.2455
Protests/Reversibility													
Doctor	14	(11.9)	45	(25.4)	16	(13.6)	30	(25.4)	9	(7.6)	2.7807	2.5804	3.0267
Health Authority	18	(15.3)	42	(35.6)	24	(20.3)	20	(16.9)	8	(6.8)	2.6250	2.4072	2.8428
Government	24	(20.3)	42	(35.6)	20	(16.9)	18	(15.3)	8	(6.8)	2.5000	2.2752	2.7248
Accuracy													
Doctor	51	(43.2)	53	(44.9)	7	(5.9)	2	(1.7)	2	(1.7)	1.7043	1.5556	1.8531
Health Authority	46	(39.0)	53	(44.9)	7	(5.9)	5	(4.2)	3	(2.5)	1.8246	1.6531	1.9960
Government	46	(39.0)	46	(39.0)	9	(7.6)	7	(5.9)	4	(3.4)	1.9018	1.7088	2.0948

Open to scrutiny													
Doctor	42	(35.6)	<u>56</u>	<u>(47.5)</u>	5	(4.2)	8	(6.8)	4	(3.4)	1.9217	1.7368	2.1067
Health Authority	49	(41.5)	<u>60</u>	<u>(50.8)</u>	2	(1.7)	2	(1.7)	1	(0.8)	1.6491	1.5209	1.7774
Government	57	(48.3)	<u>50</u>	<u>(42.4)</u>	3	(2.5)	2	(1.7)	2	(1.7)	1.6140	1.4690	1.7590
Voice													
Doctor	32	(27.1)	<u>49</u>	<u>(41.5)</u>	22	(18.6)	13	(11.0)	0	(0)	2.1379	1.9632	2.3127
Health Authority	30	(25.4)	<u>58</u>	<u>(49.2)</u>	18	(15.3)	8	(6.8)	1	(0.8)	2.0609	1.8980	2.2237
Government	44	(37.3)	<u>48</u>	<u>(40.7)</u>	15	(12.7)	6	(5.1)	1	(0.8)	1.8772	1.7113	2.0430
Consequences													
Doctor	11	(9.3)	34	(28.8)	<u>13</u>	<u>(11.0)</u>	37	(31.4)	20	(16.9)	3.1826	2.9434	3.4218
Health Authority	15	(12.7)	37	(31.4)	<u>9</u>	<u>(7.6)</u>	34	(28.8)	18	(15.3)	3.0265	2.7757	3.2774
Government	14	(11.9)	37	(31.4)	<u>12</u>	<u>(10.2)</u>	33	(28.0)	18	(15.3)	3.0351	2.7896	3.2806

Median response categories are underlined and in bold.

Table 4.3: Friedman Test Scores.

VARIABLE	P-VALUES
<i>Consistency</i>	.003
<i>Vested Interests</i>	.000
<i>Protests</i>	.000
<i>Accuracy</i>	.371
<i>Open to Scrutiny</i>	.000
<i>Voice</i>	.013
<i>Costs and Benefits</i>	.270

Table 4.4: Wilcoxon Signed-Ranks Tests.

VARIABLE	HEALTH AUTHORITY ,	GOVERNMENT,	CBA,
P-Values			
<i>Consistency</i>			
Doctor	.965	.006	.000
Health Authority	-	.000	.000
Government	*	-	.000
<i>Vested Interests</i>			
Doctor	.001	.000	.000
Health Authority	-	.012	.108
Government	*	-	.858
<i>Protests/Reversibility</i>			
Doctor	.007	.000	.011
Health Authority	-	.092	.020
Government	*	-	.003
<i>Accuracy</i>			
Doctor	.125	.038	.000
Health Authority	-	.229	.000
Government	*	-	.000
<i>Open to scrutiny</i>			
Doctor	.000	.000	.000
Health Authority	-	.363	.000
Government	*	-	.000
<i>Voice</i>			
Doctor	.326	.014	.000
Health Authority	-	.012	.000
Government	*	-	.000
<i>Costs and Benefits</i>			
Doctor	.052	.145	-
Health Authority	-	.874	-
Government	*	-	-

“-”denotes an irrelevant combination i.e. comparison of responses to one variable with the same variable.

“*” denotes a combination previously reported in the table.

“i” denotes the test was conducted against responses in the same procedural category.

“j” denotes the test was conducted against responses at the same decision-making category.

Table 4.5: Three cluster solution.

	Number of observations	Within cluster sum of squares	Average distance from centroid	Maximum distance from centroid
Cluster 1	31	605.226	4.195	8.813
Cluster 2	59	1119.729	4.141	8.013
Cluster 3	16	238.563	3.700	6.738
Cluster Centroids				
Variable	Cluster1	Cluster2	Cluster3	Grand centroid
Consistency				
Doctor	1.9677	1.7458	2.2500	1.8868
Health Authority	2.1290	1.7966	1.9375	1.9151
Government	2.5161	1.9322	2.5625	2.1981
Vested Interests				
Doctor	3.1935	1.6441	3.9375	2.4434
Health Authority	3.8065	1.7627	4.3125	2.7453
Government	4.0968	1.8983	4.4375	2.9245
Protests/Reversibility				
Doctor	2.6452	3.1186	1.8750	2.7925
Health Authority	2.2581	3.0508	1.6875	2.6132
Government	2.1935	2.9492	1.5000	2.5094
Accuracy				
Doctor	2.1935	1.5254	1.5000	1.7170
Health Authority	2.3871	1.6102	1.3750	1.8019
Government	2.4516	1.6780	1.5625	1.8868
Open to Scrutiny				
Doctor	2.0000	1.9322	1.5625	1.8962
Health Authority	1.7742	1.6949	1.3750	1.6698
Government	1.6774	1.6949	1.2500	1.6226
Voice				
Doctor	1.6774	2.3051	2.1250	2.0943
Health Authority	1.9032	2.1695	1.8125	2.0377
Government	1.7742	2.0000	1.5625	1.8679
Costs and Benefits				
Doctor	4.2581	2.9153	2.0000	3.1698
Health Authority	4.2903	2.6949	1.6250	3.0000
Government	4.1290	2.6441	2.0625	2.9906

Distances Between Cluster Centroids

	Cluster1	Cluster2	Cluster3
Cluster1	0.0000	4.6973	4.6904
Cluster2	4.6973	0.0000	5.2501
Cluster3	4.6904	5.2501	0.0000

Notes:

The sum of squares within a cluster gives a measure of compactness of the cluster.

A lower sum of squares indicates greater compactness.

The centroid is the cluster midpoint: a vector of variable means for the observations in that cluster.

Table 4.6. Multinomial Logit Regression Analysis

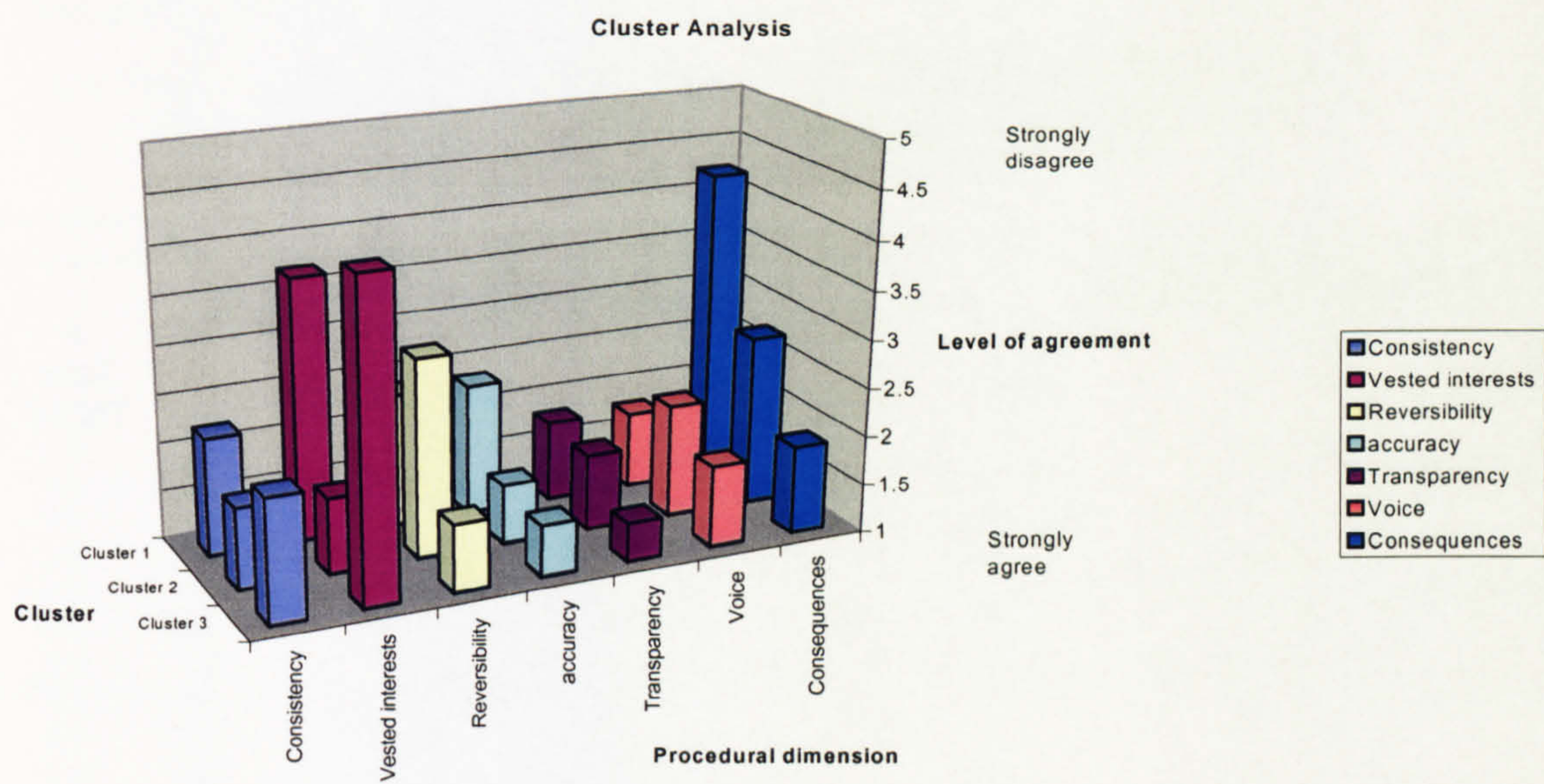
N = 93
LR $\chi^2(34)$ = 66.11
Prob > χ^2 = 0.0008
Log likelihood = -53.39182 Pseudo R² = 0.3824

Variable	Coefficient	Std. Error	z	P>z	[95% Confidence Interval]	
					Low	High
<i>Cluster 1</i>						
Female	-0.363	0.759	-0.48	0.633	-1.851	1.125
Full-time paid employment	28.373	1.189	23.86	0.000	26.042	30.704
Unemployed	72.551	1.160E+08	0.00	1.000	-2.280E+08	2.280E+08
Sick or disabled	63.928	3.160E+07	0.00	1.000	-6.200E+07	6.200E+07
Retired from work	24.154	1.912	12.63	0.000	20.406	27.902
Looking after the home	25.197	1.751	14.39	0.000	21.766	28.628
Other	28.108	.	.	.		
£10,001 - £15,000	0.003	1.567	0.00	0.999	-3.069	3.074
£15,001 - £20,000	-2.783	1.876	-1.48	0.138	-6.461	0.895
£20,001 - £30,000	-0.946	1.675	-0.56	0.572	-4.230	2.337
>£30,000	-3.089	1.800	-1.72	0.086	-6.618	0.439
30-39	-2.652	1.209	-2.19	0.028	-5.022	-0.283
40-49	-1.437	1.133	-1.27	0.205	-3.659	0.784
50-59	-1.528	1.165	-1.31	0.189	-3.811	0.754
60-69	-1.287	1.508	-0.85	0.393	-4.243	1.669
70-79	-73.886	4.820E+07	0.00	1.000	-9.450E+07	9.450E+07
90-99	-37.235	8.140E+07	0.00	1.000	-1.600E+08	1.600E+08
Constant	-24.863	2.087	-11.91	0.000	-28.953	-20.772
<i>Cluster 3</i>						
Female	-1.102	0.849	-1.30	0.194	-2.766	0.561
Full-time paid employment	64.902	3.350E+07	0.00	1.000	-6.570E+07	6.570E+07
Unemployed	202.986	1.280E+08	0.00	1.000	-2.510E+08	2.510E+08
Sick or disabled	68.876	1.040E+08	0.00	1.000	-2.040E+08	2.040E+08
Retired from work	104.785	3.350E+07	0.00	1.000	-6.570E+07	6.570E+07
Looking after the home	86.173	3.350E+07	0.00	1.000	-6.570E+07	6.570E+07
Other	11.753	6.220E+07	0.00	1.000	-1.220E+08	1.220E+08
£10,001 - £15,000	1.170	1.737	0.67	0.501	-2.234	4.574
£15,001 - £20,000	-147.742	6.090E+07	0.00	1.000	-1.190E+08	1.190E+08

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£20,001 - £30,000	-19.134	2.479E+04	0.00	0.999	-4.860E+04	4.856E+04
>£30,000	-20.203	2.479E+04	0.00	0.999	-4.860E+04	4.856E+04
30-39	-0.850	1.233	-0.69	0.490	-3.266	1.565
40-49	-0.868	1.333	-0.65	0.515	-3.481	1.745
50-59	-76.464	2.250E+07	0.00	1.000	-4.410E+07	4.410E+07
60-69	-62.708
70-79	-61.212	1.752	-34.94	0.000	-64.646	-57.777
90-99	-98.955	1.190E+08	0.00	1.000	-2.330E+08	2.330E+08
Constant	-44.473	3.350E+07	0.00	1.000	-6.570E+07	6.570E+07

Note that this analysis was performed using STATA which selects the largest of the dependent variable groups as the base (in this case cluster 2).

Figure 4.1 : Graphical Representation of Cluster Analysis.



Appendix 4.1: Hierarchical Cluster Analysis of Observations

Squared Euclidean Distance, Ward Linkage

Amalgamation Steps

Step	Number of clusters	Similarity level	Distance level	Clusters joined		New cluster	Number of obs. in new cluster
1	105	100.00	0.000	37	100	37	2
2	104	100.00	0.000	64	71	64	2
3	103	99.10	2.000	47	80	47	2
4	102	98.65	3.000	24	106	24	2
5	101	98.65	3.000	17	50	17	2
6	100	98.20	4.000	42	98	42	2
7	99	98.20	4.000	5	23	5	2
8	98	98.20	4.000	6	12	6	2
9	97	97.75	5.000	79	86	79	2
10	96	97.75	5.000	8	11	8	2
11	95	97.30	6.000	91	102	91	2
12	94	97.30	6.000	43	95	43	2
13	93	97.30	6.000	21	61	21	2
14	92	97.30	6.000	20	43	20	3
15	91	96.85	7.000	73	103	73	2
16	90	96.85	7.000	7	63	7	2
17	89	96.85	7.000	18	59	18	2
18	88	96.40	8.000	58	97	58	2
19	87	96.40	8.000	29	56	29	2
20	86	96.40	8.000	3	44	3	2
21	85	96.10	8.667	47	105	47	3
22	84	95.95	9.000	82	101	82	2
23	83	95.95	9.000	68	88	68	2
24	82	95.95	9.000	2	76	2	2
25	81	95.95	9.000	49	53	49	2
26	80	95.80	9.333	37	78	37	3
27	79	95.65	9.667	8	93	8	3
28	78	95.20	10.667	36	58	36	3
29	77	95.05	11.000	22	67	22	2
30	76	94.82	11.500	21	79	21	4
31	75	94.14	13.000	89	94	89	2
32	74	94.14	13.000	16	18	16	3
33	73	93.99	13.333	42	77	42	3
34	72	93.99	13.333	1	5	1	3
35	71	93.92	13.500	20	72	20	4
36	70	93.69	14.000	66	75	66	2
37	69	93.69	14.000	57	65	57	2
38	68	93.69	14.000	14	55	14	2
39	67	93.24	15.000	34	39	34	2
40	66	93.09	15.333	1	37	1	6
41	65	93.02	15.500	17	29	17	4
42	64	92.80	15.976	8	21	8	7
43	63	92.79	16.000	62	99	62	2
44	62	92.79	16.000	27	35	27	2
45	61	92.79	16.000	10	31	10	2
46	60	92.72	16.167	42	54	42	4
47	59	92.34	17.000	7	96	7	3
48	58	92.34	17.000	52	90	52	2
49	57	92.34	17.000	24	70	24	3
50	56	91.97	17.833	36	83	36	4
51	55	91.67	18.500	38	42	38	5
52	54	90.99	20.000	15	87	15	2
53	53	90.92	20.167	20	68	20	6
54	52	90.84	20.333	13	82	13	3
55	51	90.39	21.333	10	20	10	8
56	50	89.94	22.333	34	84	34	3
57	49	89.64	23.000	52	81	52	3
58	48	89.34	23.667	73	74	73	3
59	47	89.19	24.000	9	46	9	2
60	46	88.96	24.500	2	3	2	4
61	45	88.66	25.167	36	57	36	6

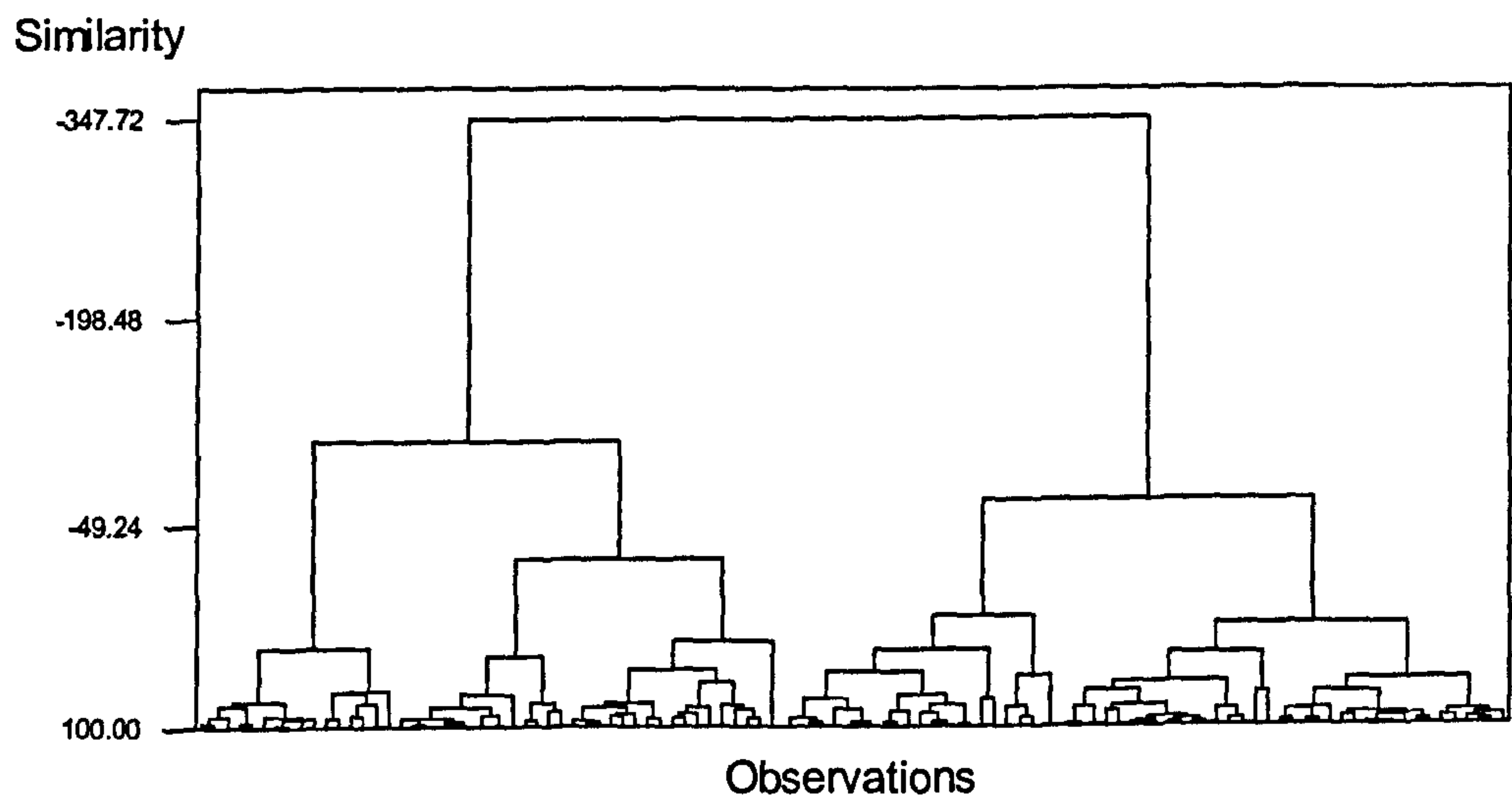
62	44	87.84	27.000	30	48	30	2
63	43	87.39	28.000	41	62	41	3
64	42	87.34	28.100	2	92	2	5
65	41	86.64	29.667	45	89	45	3
66	40	86.34	30.333	28	47	28	4
67	39	86.19	30.667	34	85	34	4
68	38	85.69	31.778	1	24	1	9
69	37	85.59	32.000	25	27	25	3
70	36	85.59	32.000	6	26	6	3
71	35	85.14	33.000	16	52	16	6
72	34	84.70	33.968	8	9	8	9
73	33	84.56	34.267	13	91	13	5
74	32	84.01	35.500	4	41	4	4
75	31	83.87	35.800	7	49	7	5
76	30	82.88	38.000	22	30	22	4
77	29	82.77	38.250	16	66	16	8
78	28	81.98	40.000	15	60	15	3
79	27	81.08	42.000	7	38	7	10
80	26	78.94	46.750	17	28	17	8
81	25	78.83	47.000	69	104	69	2
82	24	76.70	51.733	13	73	13	8
83	23	75.67	54.022	1	40	1	10
84	22	75.32	54.800	14	15	14	5
85	21	74.77	56.000	32	51	32	2
86	20	74.53	56.554	2	10	2	13
87	19	73.48	58.867	14	33	14	6
88	18	72.80	60.389	6	8	6	12
89	17	67.46	72.233	6	45	6	15
90	16	66.55	74.250	4	34	4	8
91	15	65.73	76.074	2	36	2	19
92	14	61.80	84.800	25	64	25	5
93	13	59.74	89.375	13	17	13	16
94	12	57.32	94.750	4	16	4	16
95	11	48.49	114.343	1	22	1	14
96	10	47.66	116.188	6	32	6	17
97	9	43.72	124.931	13	69	13	18
98	8	42.95	126.658	7	14	7	16
99	7	38.04	137.544	4	19	4	17
100	6	25.09	166.295	2	6	2	36
101	5	19.00	179.818	13	25	13	23
102	4	-22.98	273.015	1	4	1	31
103	3	-65.99	368.506	2	13	2	59
104	2	-109.16	464.338	1	7	1	47
105	1	-347.72	993.929	1	2	1	106

Final Partition

Number of clusters: 1

	Number of observations	Within cluster sum of squares	Average distance from centroid	Maximum distance from centroid
Cluster1	106	2692.651	4.835	10.013

Appendix 4.2: Cluster Analysis Dendrogram.



Appendix 4.2

CONFIDENTIAL HEALTH OPINIONS SURVEY.

The National Health Service does not receive enough funds to carry out all the treatments and services which people could potentially benefit from. This means that most people have to wait to receive treatment and many do not receive treatment at all. Doctors, Health Authorities and the Government all have to decide who gets treatment and how long they have to wait. We call these **priority setting decisions**.

(Health authorities are responsible for health services in their particular region.)

This survey is part of a research project being undertaken by researchers at the Open University in Milton Keynes and the University of Leicester. It asks how you think these priority setting decisions should be made. It should take no more than ten minutes to complete the survey. We would be very grateful if you could return it. *Everybody's opinion is important. Please be assured that all replies will be treated confidentially.*

We have enclosed an addressed, freepost envelope for your reply. No stamp is required. Thank you very much in advance for your assistance.



**University of
Leicester**

1. Decisions are consistent if they are made in the same way for patients whichever part of the country they live in and whenever they fall ill.

Do you agree that doctors should make priority setting decisions consistently?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that health authorities should make priority setting decisions consistently?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that the government should make priority setting decisions consistently?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

2. Someone with a vested interest is someone who would gain personally if a specific decision were to be taken.

Do you agree that doctors should make priority setting decisions without consulting anyone who might have a vested interest?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that health authorities should make priority setting decisions without consulting anyone who might have a vested interest?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that the government should make priority setting decisions without consulting anyone who might have a vested interest?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

3. Often, when a decision has been made, people who disagree with the decision will protest in some way. This might be individuals making complaints, organised protests or demonstrations.

Do you agree that that when doctors make priority setting decisions they should ignore any potential protests?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that when health authorities make priority setting decisions they should ignore any potential protests?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that when the government makes priority setting decisions they should ignore any potential protests?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

4. Accurate and precise information about the costs, effectiveness and risks involved with treatments for different patients can be complex.

Do you agree that doctors should make all their priority setting decisions with accurate and precise information?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that health authorities should make priority setting decisions with accurate and precise information?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that the government should make priority setting decisions with accurate and precise information?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

5. Some people feel that the government has a responsibility to certain individuals or groups, such as the elderly.

Do you agree that when doctors make priority setting decisions they should take account of these responsibilities?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that when health authorities make priority setting decisions they should take account of these responsibilities?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that when the government makes priority setting decisions they should take account of these responsibilities?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

6. If a decision is open to scrutiny then information is easily available to allow people to examine how the decision was made.

Do you agree that when doctors make priority setting decisions they should be open to scrutiny?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that when health authorities make priority setting decisions they should be open to scrutiny?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that government priority setting decisions should be open to scrutiny?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

7. The public and patients can be consulted in many different ways. For example, opinion polls, surveys, market research, or discussions with patients.

Do you agree that doctors should consult patients before making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that health authorities should consult the public when making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that the government should consult the public when making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

8. Some people argue that costs and benefits are important when deciding on health care priorities.

Do you agree that doctors should consider the costs and benefits of treatments when making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that health authorities should consider the costs and benefits of treatments when making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

Do you agree that the government should consider the costs and benefits of treatments when making priority setting decisions?

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
----------------	-------	----------------------------	----------	-------------------

THESE QUESTIONS ASK GENERAL DETAILS ABOUT YOURSELF. THIS HELPS US TO CHECK THAT THE OPINIONS OF DIFFERENT PEOPLE HAVE BEEN COLLECTED. REMEMBER THAT ALL REPLIES ARE ENTIRELY CONFIDENTIAL. IF YOU DO NOT WISH TO FILL THIS SECTION IN PLEASE RETURN THE REST OF YOUR ANSWERS AND LEAVE THIS SECTION BLANK,

9. Please indicate whether you are:

- Male
- Female

10. What is your age in years? _____years

11. Employment.

In full time education

In full- time paid work

Unemployed

Sick or disabled

Retired from work

Looking after the home

Other

12. What is your household income before tax? Include the income of anyone else that you live with including income from benefits.

Below £10000 per year (below £192 per week)

Between £10000 and £15000 per year (between £192 and £288 per week)

Between £15000 and £20000 per year (between £288 and £384 per week)

Between £20000 and £30000 per year (between £384 and £576 per week)

Over £30000 per year (over £576 per week).

If you would like to make any other comments please do so in the space below:

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Thank you for taking the time to complete this survey. Please send it back in the enclosed envelope. No stamp is required.

Appendix 4.3. Introductory Letter.

Dear Sir/Madam,

This letter is to ask if you would be prepared to complete a short survey which is part of a project being undertaken by researchers at Leicester University and the Open University. Your name and address have been selected randomly.

The questions are designed to find out how you think the National Health service (NHS) should make priority-setting decisions such as which treatments to provide and which patients to treat.

It should take no more than ten minutes to complete the survey and we would be most grateful if you could return it to us. We have provided an addressed envelope for your reply which requires no stamp. Please be assured that all replies are treated entirely confidentially.

Thank you in advance for your help.

Yours faithfully,

Mr. A. Wailoo
Research Associate

CHAPTER FIVE: THE UK RATIONING DEBATE AND ECONOMIC FRAMEWORKS: A CONTENT ANALYSIS OF THE PRINTED MEDIA.

5.1 INTRODUCTION

In previous chapters it has been argued that health-care rationing policy should be based on a framework of pluralism in order to accurately reflect societal preferences. Consequentialism, of which both utilitarianism and health maximisation are types, cannot adequately embody the multiple concerns which individuals hold. Evidence for this argument is drawn from a series of postal surveys of the general public which identify procedural preferences, rights and duties, *inter alia*, as concerns which, together with concerns for consequences, must be integrated into a rationing framework.

Survey evidence however, has often been viewed with scepticism by economists and health economists when used to address issues relating to health-care rationing. Health economists in particular have favoured survey evidence drawn from trade-off scenarios. In part this is a reflection of the underlying desire to reduce all components of societal preferences into a single dimension, for example in empirical work on equity-efficiency trade-offs¹. This approach however, is not appropriate in this situation; here I aim to identify the types of claims which underlie preferences for health-care rationing decisions many of which may not be reducible to the same metric as QALYs or utilities.

A further criticism of postal survey data in the context of health-care rationing comes from Dolan and Cookson (1999). They argue that 'true' preferences, which are

normatively acceptable for informing decisions such as health-care rationing, can only be established after respondents are given opportunities to discuss, reflect and deliberate². Sen (1985) refers to this concept as the reflection test of rational choice. They advocate the use of qualitative methods as a means of overcoming these criticisms and showed in a number of focus group analyses that systematic differences were evident between participants initial views and their views after discussion, Dolan *et al.* (1999)³. Coast (2001) also used focus groups and face to face interviews with the general public to identify the extent to which the general public believed they ought to be involved in health-care rationing decisions.

An alternative qualitative method is presented here which examines the content of UK media discussions of health-care rationing, which consists, at least in part, of considered attitudes rather than 'immediate' responses. Data from a sample of the UK printed media provides a proxy measure for public opinion and an insight into the underlying foundations which govern the rationing debate.

Qualitative methods in general have not been widely used by economists and the author is not aware of any study in the economics literature which uses media content analysis. Burgoyne (1999), a social psychologist, analysed media reports of one of the most high

¹ See chapter 2.

² Three criticisms of postal surveys are identified. 'Bias' is one type of potential shortcoming which is commonly addressed by practitioners of postal surveys and refers to situations where measured preferences diverge from actual ones. 'Prejudice' refers to those situations where an individuals actual preferences are not those which would be considered normatively acceptable to priority setting decisions. For example, a racist individual might favour allocating lower priorities to those from ethnic minorities. 'Soufflé' refers to those situations where an individuals actual preferences might not correspond to the true preferences of interest to social decision makers because they were arrived at using wrong information or illogical reasoning.

³ There is an acceptance of the potential for 'bias' in postal surveys, although all reasonable precautions were taken against this possibility in the work discussed in previous sections. Media content analysis is included as a means of testing the consistency of previous results using alternative data and methods. See chapter 1 for a discussion of the criticisms of survey methods in preference elicitation for rationing in health-care.

Chapter 5: A Content Analysis of the Printed Media profile health-care rationing cases, that of 'child B', Jaymee Bowen⁴. The analysis focussed on issues relating to distributive justice using a grounded theory approach. A further study by Entwistle *et al.* (1996) also focussed on the 'Child B' case, using qualitative analysis to assess the editorial stance of different newspapers and the issues that were discussed in relation to the case. For example, the analysis reported the extent and attitudes expressed in relation to the concept of opportunity cost.

The aim of this chapter is to use content analysis techniques to establish the foundations which underlie the way in which the rationing debate is discussed in the UK. Using analysis of reports drawn from a selection of UK broadsheet newspaper reports tests the prevalence with which arguments corresponding to each of the rationing frameworks discussed in previous chapters of arguments supporting and attacking each of the rationing frameworks suggested in the previous chapters are established. Section two outlines how the content analysis was undertaken and outlines the theoretical background of the chapter. Section three discusses the pilot analysis whilst the main study is discussed in section four. The results are presented in section five. Section six concludes.

5.2 METHODS

The most common approach to the analysis of qualitative data such as text makes use of Grounded Theory. This approach makes use of the qualitative data to create a categorisation of concepts, Glaser and Strauss (1967) which are subjected to continuous revisions as the analysis is undertaken. Therefore, the analysis is driven by the data rather than pre-existing theoretical considerations and is particularly susceptible to subjectivity (potentially) in coder interpretation of meanings. This approach is not

⁴ Jaymee Bowen was a ten year old girl denied experimental treatment for leukaemia in 1995 by Cambridge health authority. The case of 'child B' was seen as one of the most high profile rationing cases

considered appropriate in the current context. Rather, a content analysis is used. Categories or concepts are known prior to the analysis and have been derived in previous chapters from arguments and empirical evidence drawn from survey data. Content analysis is the systematic analysis of text and is used here to measure the occurrence of each of these concepts within the textual data, Krippendorff (1980). The analysis tests the frequency with which a number of different approaches to the problem of health-care rationing are referred to.

The analysis is based on the assumption that these frequencies accurately reflect the extent of concerns relating to each of the categories tested. However, there is no mechanism for gauging the intensity of opinions expressed; every mention of a category is treated equally. For this to cause significant bias in the analysis depends on a systematic difference being present in the mean strength of preference between each of the categories. It was not possible to test this hypothesis in the current analysis but it is noted here as a potential shortcoming, although alternative, qualitative approaches could be employed to explore this issue.

The generation of data for the analysis occurs through the coding of text into pre-existing categories. These categories were based on those developed in previous chapters and refined during a pilot process. Figure 5.1 shows the “node tree” which contains each of the categories used to code the text. Six main areas of interest are addressed: health maximisation, other types of consequentialism, rights, social contracts, cause relevance and procedural concerns. The procedural category consists of six sub-categories; transparency, accuracy, voice, consistency, absence of vested interests, and reversibility. Appendix 5.3 gives examples of text units allocated to each

of these categories. Additionally, text units were coded according to the person expressing the view contained therein. Three groups were identified; journalists, politicians and experts. This final group typically referred to clinicians or leaders of professional groups. An additional category was included which covered all other groups. Within each of these classifications the coding procedure also recorded the outlook of the viewpoint expressed, that is, whether the text was supportive or critical of the framework to which it relates.

In addition to developing the categorisation described above, the piloting process performed a number of other crucial tasks. Firstly, since all analysis took place using a qualitative research software package⁵ it was essential that text units could be retrieved electronically. The pilot analysis made use of electronically stored reports from 'The Guardian' and 'The Observer' newspapers. Using a single year, 1999, alternative search strategies were compared. The most effective strategy was considered to be that which used the terms "health" and "rationing" as keywords. Compared to eight alternative search strategies this yielded the highest proportion of relevant stories whilst generating a sufficient number of hits⁶. The pilot process also identified the appropriate text unit for analysis as the paragraph. Newspaper reports are generally written with relatively short paragraphs within which concepts of interest are expressed. The system of coding is however, sufficiently flexible to allow each paragraph to be assigned to either single, multiple or none of the categories.

The major purpose of the pilot process was to ensure objectivity in the coding of text. Two independent coders were employed to test the categorisation of text by the main coder. At the pilot stage they were provided with random samples of text which had

⁵ QSR NUDIST

⁶ See Appendix 5.1 for alternative search strategies and numbers of hits.

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been allocated to one of the categories in figure 5.1. The coders were aware that each text unit had been coded, perhaps to multiple categories, but were not aware of which category. They were asked to classify the text units into a simplified coding framework as shown in table 5.1⁷. This framework embodies the principle theoretical foundations of interest whilst presenting coders with a manageable task.

5.3 RESULTS OF THE PILOT ANALYSIS

Of the 67 hits generated by the search terms, 50 reports (75%) were considered to be relevant to the health-care rationing debate. Of these, 36 (54%) contained text units which were coded under the classification system.

Correlations between coders were calculated using two methods. The first “high level” correlation score reflects the degree to which coders are in agreement with the five parent categories (1-5 in table 5.1). A second “low level” correlation was also calculated to indicate the extent to which coders agreed between sub-categories (1.1 – 5.6 in table 5.1). Results of the pilot analysis inter-coder reliability are shown in table 5.2. The figures show that the correlation levels are remarkably similar for both independent coders and at a high level (in excess of 85% for the high level coding and in excess of 72% at the low level coding). These figures based on the pilot text analysis were taken as confirmatory evidence that no significant subjectivity was present in the coding process.

5.4 METHODS FOR THE MAIN STUDY

The years 1990, 1995 and 1999 were selected for analysis as they provide a spread of data across recent years, political and health service change. 1999 was also used in the

⁷ See Appendix B for exact details of the instructions given to independent coders.

pilot analysis, providing an opportunity to test coder reliability over time in addition to the inter coder reliability addressed both in the pilot and main studies. An electronic database, Lexis Nexis⁸, was searched using the terms “health” and “rationing”. The database covers a wide variety of UK printed media; national and local newspapers; trade magazines and professional journals. However, electronic databases are a relatively new concept and therefore a smaller number of sources were available for the 1990 and 1995 searches than for the 1999 search. This is reflected in the numbers of hits shown in table 5.3.

The total number of hits generated by the search terms totalled 54 in 1990. Only 5 national newsmedia were included in those hits and were exclusively from broadsheet newspapers. The total numbers of hits increased rapidly in both 1995 (431) and 1999 (742) for three reasons; firstly, as shown in table 5.3, a larger number of national newsmedia were included in the electronic database; secondly, an increasing number of newspaper sections became available in addition to the main news sections included in 1990; thirdly, a greater variety of local newsmedia generated additional hits although these were excluded from the analysis.

For these reasons it is not feasible to make comparisons across years based on frequencies. The purpose of including analysis for several years is to identify patterns for individual years and make tentative comparisons based only on the media common to each year.

⁸ Lexis Nexis Group (2001) See www.lexisnexis.co.uk for full details.

5.5 RESULTS

5.5.1 Inter coder reliability

In addition to the checks conducted as part of the pilot analysis, independent coders were employed throughout the main study to provide a means for assessing the objectivity of the coding used. Two coders were asked to categorise two sections of text as in the pilot analysis described above. The extent to which this correlated with the coding of the main project researcher is shown in table 5.4. Both “high level” and “low level” correlations are reported. Combining both sets of data coded indicates that the correlation dropped in the main study relative to the pilot study, significantly so in the case of low level correlation. This was particularly the case for one of the coders where this figure achieved only 36%, approximately half the level achieved in the pilot analysis (72%). Correlation with the other independent coder, whilst being lower, at 62% as opposed to 73% in the pilot analysis, was not worryingly so. Likewise, high level correlations for both coders lay within an acceptable level at 76% and 84% respectively.

Upon further inspection it was discovered that a large number of differences in coding with coder 1 occurred where text units designated as “health maximisation” had been categorised under the “other consequences” term. These examples are perhaps the most difficult to differentiate between in the analysis, particularly for the independent coders not familiar with these issues and where health maximisation was seen as a sub-category of other consequences. These text units were re-examined to check the accuracy of the original coding. No changes were made as a result. An example of the types of text unit which came into this category are given below:

“What is needed in a health service which has to ration its limited resources is the development of ‘biological’ rather than ‘chronological’

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indicators on the potential benefits of treatment. Rationing by age is not
wrong; rationing according to the ability to benefit is justified.”

5.5.2 Inter temporal reliability

The pilot analysis was undertaken in the summer of 2000 and was based on a sub-category of the sampling framework used in the main study (1999, Guardian and Observer reports). This gave an opportunity to test the reliability of coding undertaken by the main researcher on identical text units after a period of one year had elapsed. Those text units coded in the pilot analysis were matched with those coded in the main study. Table 5.5 shows the results of this analysis.

A total of 57 text units were identified which had been coded in both analyses. Not all text units were discovered since the different databases used generated slightly different results. Again, both high and low-level correlations were calculated and both achieved figures in excess of 85%.

5.5.3 Analysis of categories

Table 5.7 shows the frequency with which each of the 6 major categories occur in each of the three years. The analysis is then further divided to take into account the six individual, procedural categories. Counts, which are presented both in absolute terms and as a percentage of the total number of coded text units in any given year, indicate that the text unit contained reference to opinions or arguments that corresponded to a particular concept. The analysis at this level does not reflect the type of attitude expressed in relation to the concept, that is, whether the report is critical, neutral or supporting of the concept. These counts are reported here as an indication of the general terms in which health-care rationing issues are debated in the UK media.

The most frequently discussed concepts are procedural in nature. This category was the largest in both 1995 (52%) and 1999 (57%) and was the second largest in 1990 (34%). The combined total for this category comprised over 54% of all relevant text units. Health maximisation was the second most frequently mentioned health rationing approach across the three years comprising 27% of relevant text units in total. This was the largest category in 1990 (43%). Relative to these two main categories the results show that none of the arguments categorised under either consequences, rights, cause relevance or social contracts consisted a significant proportion of text units categorised. When combining results across the three years none of these categories managed to exceed 10% of total coded text units (4%, 10%, 2% and 7% respectively). This was not universally the case for each of the three individual years. For example, almost 15% of text units were coded as corresponding to issues of cause relevance.

There was also great variability between procedural categories. Three of the categories (transparency, voice, and consistency) registered 20%, 16% and 18% respectively across the three years, whilst accuracy, absence of vested interests and reversibility were only considered relevant to 1%, 4% and 10% of text units respectively.

5.5.4 The standpoint of coded text units

Within each of the six main categories and the further six subcategories of procedures discussed above, text units were classified according to the polarity of the argument and the type of person expressing the opinion. Four broad groupings were used; journalists, politicians, experts and others. Tables 5.8.-5.10. show the results of this analysis for each of the three sample years. Table 5.11 shows the results of the classification pooled over the three years.

Firstly, analysis of the overall polarity of the arguments used in each category reveals that, in addition to the fact that procedural issues constitute the largest category, rarely are opinions expressed against the relevance of any procedural category. In 1990 just one of the thirteen text units discussing issues of procedure did so in a negative fashion. In 1995, 6.25% (12/192) of text units coded under the “procedural” category were negative and in 1999 the equivalent figure was 0.7% (2/290). On the rare occasions that particular dimensions of procedure are opposed these have been in relation to the categories of transparency (open to scrutiny) and voice. Examples of such opinions are given below:

“These are very rough, very tough choices. But they should not be made on an ad hoc basis. The public should understand what is happening. In this country, the public seems happy to leave the decisions to other people. One experiment to open up a debate into rationing in Hackney, north London failed because of lack of interest. Three people turned up to a meeting although 3,000 homes had received leaflets.”

The Independent (London), March 11, 1995, Saturday. [Anti voice, ‘other’ standpoint but also coded as pro-voice, journalistic standpoint]

“Proposals: Their document, Building On The Best Of The NHS, finds present health authorities “unacceptable and unaccountable”, and proposes a new appointments process. It urges greater use of focus groups, opinion surveys and local referenda, but rejects involving consumers in rationing as “dangerously simplistic”. Conference later voted for local authorities to take on commissioning role”.

The Guardian, 1st November. [Anti-voice]

“The language of rationing is everywhere now in the NHS - except on the lips of Virginia Bottomley, or any other politician in any party. Those who manage the budgets she sets have no choice but to set priorities, though the Government denies the need for a full and honest public debate about it. Ms Perry says the need to talk about rationing is becoming acute. For example, in a few months a new drug for multiple sclerosis, beta interferon, will get its licence. It will cost about pounds 7,000 a year to delay the progress of the disease for two or three years in some cases, but it is not a cure. Bromley estimates that it would cost between pounds 2m and pounds 4m a year for its MS patients. Should it offer it to all who want it?

The Independent, May 3rd. [Anti-transparency]

This reinforces the impression discussed in the previous section that procedural issues not only dominate the terms in which issues of health-care rationing are debated but that the vast majority of this debate supports the aspects of procedures that have been emphasised throughout this thesis.

The previous section also identified that issues of health-care rationing are frequently discussed in terms of health maximisation. However, further analysis in this section reveals that a significant proportion of that debate is centred on opposition to the relevance of capacity to benefit as a determinant of health-care entitlements. Furthermore, this categorisation was deliberately weak in order to bias in favour of the issues here. For example, arguing that capacity to benefit is important is sufficient for inclusion in this category, although this does not necessarily equate with health maximisation. Effectively, arguments supporting necessary but not sufficient conditions

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for health maximisation were included in this section. In 1990, 38% (5/13) text units which were relevant to the concept of health maximisation were considered to be arguing against the relevance of the issue in health-care rationing. This figure compared with 21% in 1995 (22/103) and 38% (24/63) in 1999.

Examples of such anti-health maximisation opinions are as follows:

The dry jargon of the market hides decisions about people which are acutely sensitive, none more so than the concept of rationing - that there may be certain treatments or services that a health board may decline to fund on the grounds that these are medically inappropriate or cannot be justified within available resources. Three weeks ago a Cambridgeshire health authority refused to fund leukaemia treatment for a 10-year-old girl, primarily on medical grounds but using the language of accountancy to explain that the money could be better spent elsewhere.

The Scotsman, March 26th, 1995.

He said: "Qualys may be useful in theory for comparing the value of one coronary bypass as against 20 hernia operations, but when you are eyeball to eyeball with a patient such calculations go out of the window."

Sunday Times, June 24th, 1990.

"It is, by any economic measure, entirely logical, but it is less easy to defend on a humanitarian scale. Try explaining to an old lady, who is in great pain and effectively crippled because she needs a new hip joint, that she does not have enough Qalys in the bank. Not easy."

Sunday Times, November 14th, 1999.

The prevalence of opinions which are against health maximisation as a basis for health-care rationing confirms procedural issues as the category of primary importance in media discussion of health-care rationing issues. In table 5.11, the net references (total positive less negative) column indicates the true extent of this dominance of procedural issues. Procedural issues register a net count of 480 text units over the three year period in contrast to the 128 compatible with health maximisation. Two of the procedural sub-categories, transparency and consistency, generate a greater net score than health maximisation and third sub-category, voice, is slightly lower (112 text units).

Analysis according to the standpoint of coded text units reveals for two further categories, rights and social contracts, that although they are mentioned relatively infrequently, when they are this is almost entirely to promote their importance to rationing of health-care. In total, 4 text units argue against the relevance of rights and just one condemns the relevance of social contracts. Furthermore all of these articles were from 1995.

What was missing from Mr Laws's reported comments was any sense of how the NHS - and all other health services - operate. It was as though his ears have been shut to the nationwide debate over how health resources should be rationed. He referred to the "over-riding priority" of a child's fundamental "right to life", as though the health service is able to save all its patients. It cannot. All manner of secret rationing goes on: elderly patients are denied access to intensive care units, diabetic patients refused renal dialysis, and alcoholics turned down for liver transplants. Even America - which spends twice as much as Britain - strictly rations transplant

operations. Earlier rationing decisions came clothed as "clinical decisions".

Some people would prefer the old system was still in place. Sir Raymond Hoffenberg, former President of the Royal College of Physicians, has stated:

"If services are to be limited, I would rather see it done implicitly - unstated, unwritten, unacknowledged - in the curious and not inhumane way in which such matters are managed in the UK."

Daily Telegraph, March 23rd, 1995.

Perhaps surprisingly, there was no support for refusing smokers the right to pounds 5,000 heart by-pass operations and little support for allowing it only if they gave up smoking - the main objection being the condition's doubtful enforceability.

The Guardian, May 10th, 1995.

The remaining two categories, "other consequences" and "cause relevance", register negative net scores, that is more text units were identified where the opinion expressed was against the inclusion of these issues as a basis for rationing than those which promoted the relevance of the issue. In total this amounted to -39 and -7 respectively. In both cases a number of these counts were generated by the high profile case of Viagra where quotes such as that below were common following the intervention of the then Health Secretary Frank Dobson:

As Dobson compassionately put it, 'impotence is neither life-threatening, nor does it cause physical pain'. And, he mercifully decreed, that 'in exceptional circumstances, where impotence is causing severe distress', a hospital

specialist who'd never met the patient before could decide if the patient was upset enough to get it.

The Guardian, April 27th, 1999. [Anti-other consequences, political viewpoint but also coded as pro-other consequences, journalistic viewpoint]

The drug joins a list of restricted medicines, schedule 11, but Viagra is the first to be restricted on the basis of the cause of illness, which could be difficult to justify objectively. Other drugs are listed because there are better or cheaper treatments or, in the case of temazepam, because of concerns about abuse.

The Guardian, May 27th, 1999 [Anti-cause relevance]

The dominance of this issue in a particular year may indicate that the negative net counts for these categories is misleading, although a similar negative result is found in 1995 for the category of “other consequences”, where more general objections to the principle of including non-health benefits in rationing decisions were made. The extract below exemplifies:

If a man wants to become a woman, he can have the operation privately. If someone is too fat, they can go on a diet and not expect the rest of us to pay for stomach tucks and liposuction. If a woman happened to be at the back of the queue when they were handing out cleavages, then she can get her breasts enlarged at her expense. And if a man is stupid enough to have 'I love Doris' tattooed on his arm during a brief fling then he should not expect it to be removed on the NHS simply because his latest flame happens to be called Betty.

Daily Mail, September 1st.

5.5.5. Comparisons between groups

Throughout the three years, most text units were coded into one of the three main groups; the journalist, politicians or experts. The remaining “other” category was the smallest category in almost every case. Furthermore, the general case was that no stakeholder group exhibited marked deviations either in the frequency with which they expressed opinions about particular categories or the tone of the arguments they used when referring to those categories.

Two exceptions to this tendency are worthy of note, both of which are relevant to politicians. Firstly, there is a complete absence of rights talk from this group. Just one reference across the entire three year period is identified. Secondly, politicians also tend to support the relevance of cause in contrast to the combined negative score for this category. This tendency is particularly strong in the 1999 text where 8 of 10 units support the relevance of cause.

5.5.6 Summary and discussion of results

The primary indication of these results is that a focus on health maximisation is excessively narrow to capture even the main principles governing the way in which the UK rationing debate is conducted. Allocation to this category was done so on the basis that the text unit addressed a necessary but not sufficient condition for health maximisation, yet the frequency of this category failed to match that of procedural concerns, principally comprising voice, transparency and consistency. When the polarity of the opinions expressed within these text units is taken into account the importance of procedural considerations dominates further. Issues of rights and social contracts contribute only a small proportion of coded text units. Furthermore, the combined analysis indicates that neither consequences generated in excess of health

benefits, nor the relevance of causes are considered appropriate to health-care rationing entitlements.

The analysis supports that of previous chapters in general. Health-care rationing decisions cannot be made without reference to the outcomes that are generated but health maximisation is not an appropriate description. Pluralism is again advocated by the analysis although the extent to which rights and social contracts must be included is debateable. The data which combines all stakeholder groups implies this weight should be low. However, it is interesting to note that the counts associated only with the “other” category, where expressions of opinion from the general public are coded, suggest this weight should be substantial.

The case for detailed investigation into the role of procedural preferences is clear from the analysis. Whether these are pure procedural preferences, to borrow the language of John Rawls (1971), or are predominantly instrumental in nature, the analysis cannot identify but this is a clear prescription for future work.

There is a tendency for qualitative research of this type to be dismissed on the basis of the subjectivity which arises at the coding stage. Every attempt has been taken to avoid this bias and the correlations achieved between coders confirms this. Additionally, unlike frequently used classification methods such as grounded theory, no subjectivity was introduced when deciding on categories since these were driven entirely by theories generated in previous chapters of this thesis and were not changed after the analysis began.

However, a number of assumptions have been made in interpreting the results. Counts of frequencies within text are somewhat blunt; analysis cannot differentiate between the strength of arguments expressed in the text. Each count has been assumed of equal strength throughout the analysis. The validity of this assumption could be examined further in a qualitative analysis but it is the contention here that content analysis can provide a meaningful insight into the types of frameworks which are used in the health-care rationing debate.

5.5 CONCLUSION

The content analysis presented here attempts to identify the frameworks which characterise the way that health-care rationing is debated in the UK printed media. Whilst this is a rarely used research method in economics, it is an important tool in the context of health-care rationing. The general public are not familiar with making these types of choices and it may therefore be the case that alternative methods of identifying public opinion cannot be relied on. Media reports are generally based on considered opinions and the content analysis presented here allows inferences to be made regarding public preferences. The chapter also provides triangulation of evidence generated in previous chapters.

The general frameworks that describe the way in which health-care rationing is discussed in the UK media, and by implication the way in which the issue is conceived of by the general public, are not exclusively consequential. The issues identified here lend general support for a pluralistic approach: an integration of concerns for health outcomes and procedures, and to a lesser extent rights, causes and social contracts. There appears to be little evidence to support including consequences that extend beyond health outcomes. These findings should be viewed as support for the data

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generated from surveys of public opinion described in previous chapters and as
identifying a future research agenda which includes issues of how to integrate these
competing claims.

5.6 REFERENCES

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Table 5.1: Coding Framework

NODE COMPONENT	DESCRIPTION	TEXT EXAMPLES/POSSIBLE KEY WORDS
<i>Theoretical Frameworks</i>		
1. Maximisation	The maximisation of a certain goal within cost constraints	“Biggest bang per buck”, bias against elderly people on grounds that they cannot benefit for as long as young, cost importance (anti-cost is anti-consequentialist), those who say entitlements should be solely on clinical need are anti-maximisers.
1.1 Health maximisation (sub-category of maximisation)	The maximisation of some concept of “health”, which may be measured in terms of QALYs. Sub – category of the above. Only code as health max if it specifically refers to it, otherwise it is just “maximisation”.	Cost-effectiveness, importance of ability to generate health gains, rejecting certain treatments because they are not health e.g. viagra
2. Rights	Access to care premised on a “higher level” claim which operates irrespective of potential net gains or losses in terms of consequences.	Rights, patients charter, litigation
3. Social Contracts	Those who have contributed to the funding of the health service through tax and national insurance have an implicit contract with the state that should determine their entitlements to NHS services.	Paid into the NHS all their lives, National insurance, tax
4. Cause relevance	Conditions which are in some way “self-inflicted” receive a lower priority	Viagra limited by cause of impotence, smokers drinkers and HIV denied treatment on moral grounds,
5. Procedural Concerns		
5.1 Transparency (open to scrutiny)	The basis by which rationing decisions are reached should be available for others to scrutinise	Criteria made public, reasons made explicit, accountability, patients who want to know “why?”, hold the NHS to account, openness, “letting people know”, transparent,
5.2 Accuracy	The information on which rationing decisions are based must be of good quality	Proof, accurate information,
5.3 Votes/Voice	Public inputs into decision-making process either directly or by representatives	Public consultation, surveys, patient/public participation, involvement,
5.4 Consistency	Geographical, temporal or inter personal uniformity	Discrimination by postcode, inequalities in treatment for reasons other than clinical outcomes e.g. some doctors blocking abortions because they object,
5.5 Vested Interests	Decision-making should have systems which deal with the	Power in the hands of those with competing incentives,

5.6 Reversibility	problem of those who have a vested interest in seeing certain health rationing outcomes	Ability to appeal, evidence of doctors or politicians changing their minds, bowing to pressure,
	Rationing decisions should be challengeable	

Table 5.2: Inter coder reliability based on pilot content analysis.

	High-level correlation		Low level correlation	
	N	%	N	%
Coder 1 (36 text units)	32	88.88	26	72.22
Coder 2 (63 text units)	54	85.7	46	73

Table 5.3: Main project hits and sources by year.

Year	Hits	Times	Guardian	Independent	FT	Telegraph	Mail	Scotsman	Mirror	Record	express
1990	54	Y	Y	Y	Y	Y	N	N	N	N	N
1995	431	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
1999	742	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 5.4: Inter coder reliability

	Part 1						Part 2						Combined			
	High Level		Low level		High Level		High Level		Low level		High Level		Low level		High Level	
	correlation	%	correlation	%	correlation	%	correlation	%	correlation	%	correlation	%	correlation	%	correlation	%
Coder 1 RW (119 codes)	28/42	67	14/42	33	62/77	81	29/77	38	90	76	43	36				
Coder 2 RC (147 codes)	34/44	77	24/44	55	89/103	83	67/103	65	123	84	91	62				

Table 5.5: Intertemporal reliability

1999 all		
	%	n
High level	89.47	51
Low level	85.96	49
N=57 matching text units		

Table 5.6: Proportions of relevant articles

		1999	1995	1990	Total
Relevant					
Text units	459	338	41	838	
Articles	203	158	12	373	
Not relevant – articles (%)	83	11.19	23.67	70.37	223

Table 5.7: Counts by aggregate category.

Counts	1999		1995		1990		Total	
	N	%*	N	%	N	%	N	%
Health Max - units	87	18.95	121	35.79	18	43.90	226	26.97
articles	74		80		6		160	
Rights - units	15	3.27	19	5.62	1	2.44	35	4.18
articles	14		18		1		33	
Other consequences - units	54	11.76	24	7.10	4	9.76	82	9.79
articles	41		19		3		63	
Social contracts - units	12	2.61	6	1.78	0	0	18	2.15
articles	11		5		0		16	
Cause relevance - units	47	10.24	8	2.37	6	14.63	61	7.28
articles	35		7		3		45	
Procedures - units	265	57.73	177	52.37	14	34.15	456	54.42
articles	145		102		7		254	
Open to scrutiny - units	84	18.30	77	22.78	9	21.95	170	20.29
articles	58		56		6		120	
Accuracy - units	4	0.87	1	0.30	1	2.44	6	0.72
articles	4		1		1		6	
Voice - units	53	11.55	77	22.78	3	7.32	133	15.87
articles	39		55		2		96	

Consistency - units	128	27.89	23	6.80	0	0	151	18.02
articles	88		23		0		111	
Absence of vested interests - units	13	2.84	18	5.33	1	2.44	32	3.82
articles	11		15		1		27	
Reversibility -units	10	2.18	6	1.78	0	0	16	1.91
articles	7		6		0		13	

* percentage of relevant text units

Table 5.8: Analysis of 1990

Text units only	Opinion				Political				Expert		Other	
	All pro	All anti	pro	anti	pro	anti	pro	anti	pro	anti	pro	anti
Health Max	13	5	6	2	1	0	6	3	0	0	0	0
Rights	1	0	1	0	0	0	0	0	0	0	0	0
Other consequences	4	0	1	0	0	0	3	0	0	0	0	0
Social Contracts	0	0	0	0	0	0	0	0	0	0	0	0
Cause relevance	6	1	2	1	1	0	3	0	0	0	0	0
Open to Scrutiny	8	1	3	0	0	0	5	1	0	0	0	0
Accuracy	1	0	0	0	0	0	1	0	0	0	0	0
Voice	3	0	3	0	0	0	0	0	0	0	0	0
Consistency	0	0	0	0	0	0	0	0	0	0	0	0
Absence of vested interests	1	0	0	0	0	0	1	0	0	0	0	0
Reversibility	0	0	0	0	0	0	0	0	0	0	0	0
All Procedures	13	1	6	0	0	0	7	1	0	0	0	0

Table 5.9: Analysis of 1995

Text units only	Opinion				Political				Expert				Other			
	All pro	All anti	pro	anti	pro	anti	pro	anti	pro	anti	pro	anti	pro	anti	pro	anti
Health Max	103	22	32	12	23	4	46	4	2	2	2	2				
Rights	15	4	5	4	0	0	7	0	3	0	3	0				
Other consequences	3	21	2	11	0	5	0	4	1	4	1	1				
Social Contracts	5	1	4	1	1	0	0	0	0	0	0	0				
Cause relevance	7	1	3	0	0	0	3	0	1	0	1	1				
Open to Scrutiny	76	3	31	0	11	1	31	2	3	2	3	0				
Accuracy	1	0	0	0	0	0	1	0	0	0	0	0				
Voice	69	8	28	3	11	3	25	2	5	2	5	0				
Consistency	22	1	6	1	9	0	4	0	3	0	3	0				
Absence of vested interests	18	0	9	0	4	0	5	0	0	0	0	0				
Reversibility	6	0	3	0	0	0	3	0	0	0	0	0				
All Procedures	192	12	77	4	35	4	69	4	11	4	11	0				

Table 5.10: Analysis of 1999

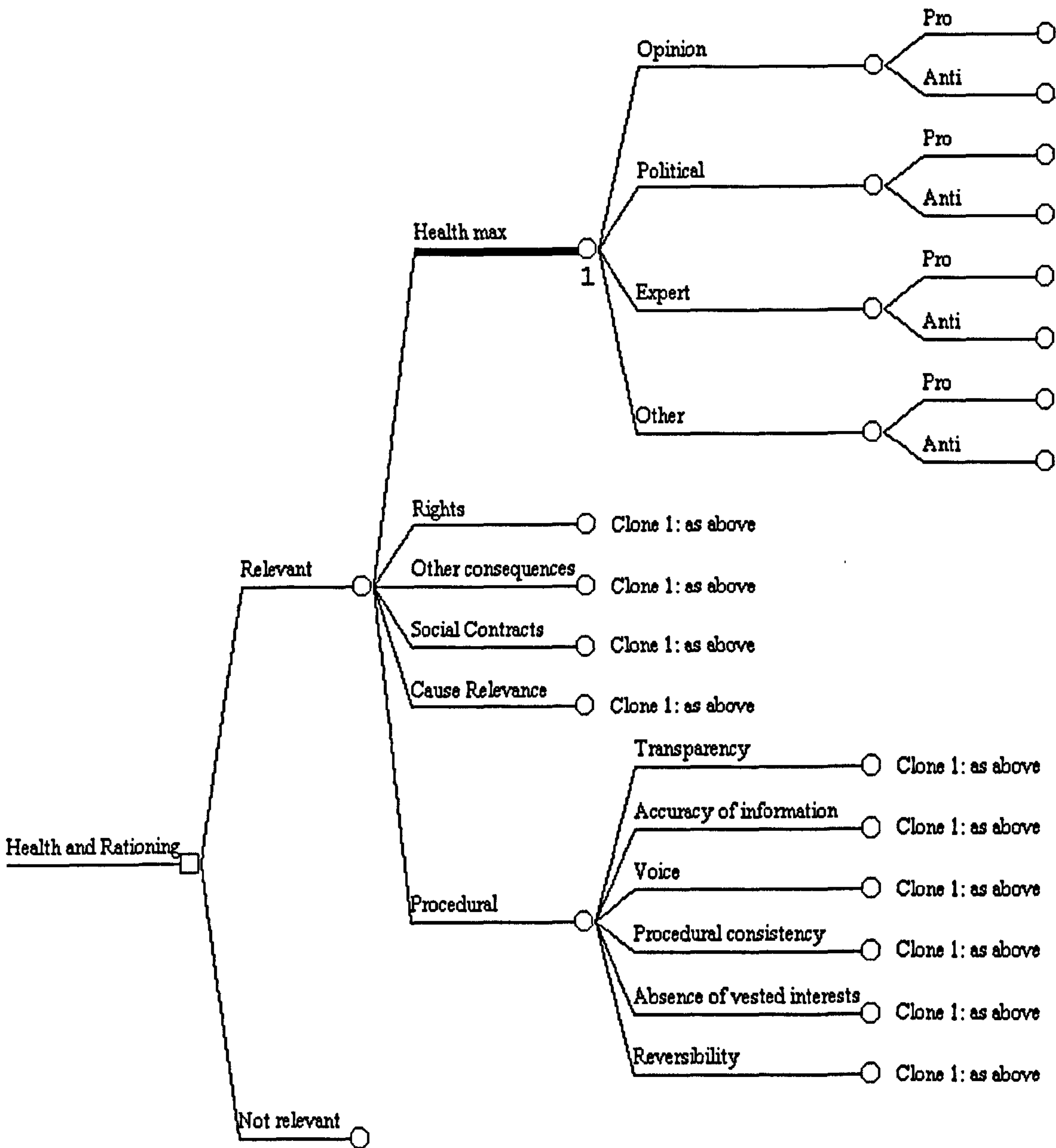
Text units only	Opinion				Political		Expert		Other	
	All pro	All anti	pro	anti	pro	anti	pro	anti	pro	anti
Health Max	63	24	27	16	10	2	21	1	5	5
Rights	15	0	7	0	1	0	4	0	3	0
Other consequences	15	40	10	12	3	15	1	8	1	5
Social Contracts	12	0	4	0	0	0	1	0	7	0
Cause relevance	15	33	7	12	8	2	0	17	0	2
Open to Scrutiny	83	1	40	1	6	0	34	0	3	0
Accuracy	4	0	1	0	0	0	3	0	0	0
Voice	51	1	27	1	4	0	17	0	3	0
Consistency	129	0	70	0	20	0	25	0	14	0
Absence of vested interests	13	0	4	0	4	0	4	0	1	0
Reversibility	10	0	4	0	2	0	3	0	1	0
All Procedures	290	2	146	2	36	0	86	0	22	0

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Table 5.11: Analysis of all years combined

Text units only	Opinion				Political		Expert		Other	
	All pro	All anti	pro	anti	pro	anti	pro	anti	pro	anti
Health Max	179	51	65	30	34	6	73	8	7	7
Rights	31	4	13	4	1	0	11	0	6	0
Other consequences	22	61	13	23	3	20	4	12	2	6
Social Contracts	17	1	8	1	1	0	1	0	7	0
Cause relevance	28	35	12	13	9	2	6	17	1	3
Open to Scrutiny	167	5	74	1	17	1	70	3	6	0
accuracy	6	0	1	0	0	0	5	0	0	0
Voice	123	9	58	4	15	3	42	2	8	0
Consistency	151	1	76	1	29	0	29	0	17	0
absence of vested interests	32	0	13	0	8	0	10	0	1	0
Reversibility	16	0	7	0	2	0	6	0	1	0
All Procedures	495	15	229	6	71	4	162	5	33	0

Figure 5.1: Coding Tree



Appendix 5.1:

Search strategies employed and hits generated.

Type of Search	Search terms	Hits Generated
Keyword	Health AND Rationing	67
	Health AND priority	212
5 word proximity	Health W5 priority	23
	National AND Institute AND	48
	Clinical AND Excellence	
5 word proximity	Health W5 Care AND	3
	Restrict	
5 word proximity	Health W5 Care AND Ration	4
	NHS AND Ration	7
	NHS AND Waiting	180
	NHS AND Waiting AND list	59

APPENDIX 5.2**INSTRUCTIONS TO CODERS**

1. You have been presented with a table which has twelve different categories described in it. Each of these categories relate to different types of arguments that have been used to discuss issues surrounding health-care rationing. Please read the descriptions of each of the concepts and the examples/key words which might be used in relation to these arguments. The purpose of this section of the research is to check that the coding of text into these categories is objective i.e. do you code the text into the same categories as I have?
2. If you are not clear about the meaning of any of these concepts than please ask me to clarify the meaning before you do anything else. This is crucially important since if your understanding of a concept differs from mine we will not agree on coding. The key words and concepts only refer to things which might indicate a certain category, not that it necessarily denotes a particular categorisation.
3. The other booklet contains a selection of paragraphs which have come from newspaper reports. Your task is to go through each paragraph in turn and allocate it to at least one of the categories. For example, if you think the first paragraph is concerned with peoples rights when health-care is rationed then put a '2' next to it. If you think a paragraph is referring to consistency of decision-making, then put 5.4 next to the paragraph. More than one concept can be contained in a paragraph but each of the paragraphs contains at least one concept.
4. The opinion expressed may be either in favour, or against a certain concept. Code each in the same way.
5. Hopefully you will come up with the same answers as myself but this needs to be achieved independently. Therefore, make sure you are clear about the categories before you start.

Appendix 5.3. Examples of text units coded as positive examples for each node.

Health Maximisation

What should be done? Back in 1997 when Labour was in opposition, its shadow health secretary promised to set up an inquiry into ageism. This would be an important first step in a society in which the over 65s will increase at 10 times the overall rate of the population in the next 40 years. No one should be excluded from health treatment on age grounds alone, because ageing does happen at a uniform rate. What is needed in a health service which has to ration its limited resources is the development of 'biological' rather than 'chronological' indicators on the potential benefits of treatment. Rationing by age is wrong; rationing according to the ability to benefit is justified.
The Guardian, November 8th, 1999.

Rights

Supporting this view, Ms Anna Coote, deputy director of the IPPR, used the conference to call for the establishment of a national health commission, with clear guidelines and a set of 'enforceable rights for patients and would-be patients', which could be used to provide a framework for decision-making on health policy issues.
Financial Times, November 22nd, 1995.

Other consequences

However, your editorial risks perpetuating the myth that there is a class of "lifestyle drugs" that are somehow different to other therapies and which merit different policy considerations. This view is mistaken. Male erectile dysfunction (or impotence) is an illness just like any other. It has many potential causes but, whatever the cause, is distressing and deserves proper treatment if available.
Financial Times, June 8th 1999.

Social Contracts

I knew his chances of survival there were minimal; but none of my arguments - that he was in fine condition for his age, that he was an old soldier who had served his country - persuaded the surgeons to accept him. So he went to the geriatric ward, and died there.
Daily Mail, November 9th 1999

Cause Relevance

They were divided into three main categories - essential services such as maternity care and head injuries; very important services such as hip replacements and those "valuable to certain individuals but significantly less likely to be cost- effective or to produce long- term gain" such as advanced cancer with poor survival prospects. The list showed a clear bias against conditions with a self-inflicted component with diseases related to smoking and alcohol abuse faring badly.
The Scotsman, March 11th 1995.

Procedural Transparency

The case demonstrates that these health authorities are at least open to question by the courts. But the public, which provides the funds, knows little of what determines the choices that are made. The group of individuals that chooses between, say, buying more hip replacements or extra coronary bypass operations is shrouded in mystery and obscurity. Yet health authorities now rank among the most important institutions in the country. The issue of health priorities has become highly politicised. Once, decisions were the preserve of the doctors. Now they are fought out in the courts, in Parliament, on television and in the press. But the key decision-making bodies in the NHS do not as yet enjoy public confidence. The only way forward is a more transparent and accountable NHS - perhaps with an elected element among its officials - in which ordinary people play their part in setting priorities. This would mean that none of us could shirk responsibility for harsh choices that will have to be made about who gets what in the future NHS.

The Independent, March 11th 1995.

Accuracy

Professor David Webb, chairman of Lothian Health's area drug and therapeutics committee, defends his board's tough stance on drug funding. "Any decisions by Lothian Health are made with the advice of the relevant experts after due consideration," he said.

Sunday Times, July 4th 1999

Voice

Oregon's style may be unacceptable in Britain, but in one sense its method is admirable. At least the general public can discuss alternatives. In comparison, today, after months of political battle, as the Government details the latest stage of its reforms by naming the first self-governing hospital trusts, the average Briton is still mystified about the possible options.

The Independent, December 4th 1990

Consistency

When a woman walks into her GP's surgery, she has no idea how her health authority judges eligibility for free treatment. In some areas, for example, a woman automatically qualifies for a free abortion if she is under 16; in others, she may qualify if she is under 21. And while one authority may consider 'failed contraception' just cause, another may stipulate 'severe mental health problems'. As a result, huge regional differences now exist. For instance, in 1996, according to an ALRA report, Tees in the north-east provided 97% of all abortions on the NHS, while Redbridge and Waltham Forest in the south-east provided just 34%.

The Guardian, June 24th 1999

Absence of vested interests

Who, then, is to decide who gets them and who does not? For the doctors' trade union, the BMA, as selfish and irresponsible a vested interest as the worst of the flying pickets

in the 1970s, the answer is simple: doctors. For the BMA, the question of who should pick up the tab is equally simple: their members' employer, the taxpayer. The Independent, January 23rd 1999.

Reversibility

Article 6 of the convention states that "everyone is entitled to a fair and public hearing, within a reasonable time, by an independent and impartial tribunal." But the new NHS complaints procedure, introduced three years ago, means that patients in the first instance will have their complaint considered by the people complained against - a system which the health watchdogs deem neither fair nor public. The Scotsman, September 1st 1999.

CHAPTER 6: CONCLUDING REMARKS

6.1 SUMMARY

Hitherto, the economics of health-care rationing has been dominated by QALY maximisation. The extent to which this approach now influences health-care in practice is substantial. The approach is based on, but not coterminous with, utilitarianism and there are, therefore, substantial parallels between this approach and traditional welfare economics.

Welfarism however, is not universally accepted as a normatively appropriate basis for decision-making. As illustrated in chapter 2, numerous challenges to the QALY maximising approach have been made but, at least for those emanating from within health economics, these have remained almost exclusively within a consequentialist framework, focussing on social preferences for alternative distributions of health-care and health outcomes. The few who have promoted thinking that goes beyond this consequentialist approach include Anand (1999), Daniels (2001), Mooney (1998) and Sen (2001). This thesis has attempted to build upon approaches such as theirs by highlighting the relevance of deontological and procedural issues.

Evidence that citizen preferences are not adequately described by consequentialist frameworks has been presented both from survey data and content analysis of printed media. Together, both sources of evidence suggest that a number of alternative non-consequentialist criteria are relevant to health-care rationing.

Content analysis of media reports (chapter five) suggests that procedural preferences are of particular relevance in the context of health-care rationing, with references to this framework exceeding those of all others. Specifically, the procedural characteristics of transparency, voice and consistency were found to be the most frequently discussed concepts. Survey evidence corroborated this finding (chapter four), with accuracy of information a further procedural category which respondents indicated was also relevant. In addition, survey data suggest that procedural preferences may outweigh consequential considerations and that preferences across different dimensions of procedures differ according to the level at which decisions are made. Evidence in chapter three, which specifically addressed “voice” as one example of a procedural characteristic, provides evidence that respondents were willing to violate health maximisation in favour of an option favoured by a procedural approach.

Across the three data sources discussed, support for health maximisation is weak although it is important to restate that this does not imply that individuals are unconcerned with health outcomes. In chapter three, there is a clear rejection of health maximisation on aggregate but a significant proportion of respondents do choose this option when potential health gains are very different between groups. Interestingly, the proportion of those supporting the health maximising option in these situations is stronger than the support that is shown for the broader categories of consequentialism that were tested. This finding was consistent with that of the content analysis. Here, the “other consequences” category was one of only two categories that received a net negative score (the sum of the number of statements in support of this approach was less than the sum of the number of statements against). The implication of this finding is that

measures of health outcome, as opposed to broader utility measures, are relevant to the pluralistic framework that has been advocated.

Cause relevance is a theme that occurs with relative infrequency in the media, implying that this group of concerns are unimportant. The majority of occasions that these issues are brought up in the media is in a negative fashion, that is to argue against the relevance of cause in determining health-care entitlements. Again, this is consistent with data drawn from survey questions. Responses varied across the different scenarios presented which addressed different types of causes. In several of the scenarios, respondents were closely split on whether the issue was of relevance, whilst in the questions framed in a more general manner, respondents were more clearly against including cause as a determinant of entitlements.

Only a small amount of support can be found for healthcare rights and social contracts. These issues did not feature strongly in media coverage, although when they were discussed almost all individuals expressed strong support for the view that they should determine health-care entitlements.

In combination, the three sets of empirical evidence and arguments suggest that consequentialism is not acceptable to the general public as the sole basis for decision-making in health-care rationing situations. This, in itself, represents a substantial departure from the methods that have been employed by the majority of economists addressing this issue. Indeed, welfarism in general is based on a consequentialist foundation. In particular, procedural preferences have rarely been discussed outside the fields of social psychology and legal studies. The refinement of a taxonomy of

Chapter Six: Concluding remarks

procedural preferences in the context of health-care is both novel and valuable, particularly given the relevance of this work to the increasingly discussed procedural approach of the philosophers Norman Daniels and James Sabin¹.

6.2 IMPLEMENTATION

6.2.1. Establishing Trade-offs

Many economists would argue that it is not sufficient to simply recognise the importance of competing claims to resources but that the trade-offs between these claims must be estimated. In Williams' (1997) early attempt to quantify a trade-off between efficiency and the notion of equity embodied in the 'fair innings' approach, he argued that policy-relevance necessitates such quantification: without it, the debate cannot proceed beyond discussion of "vaguely appealing but ambiguous slogans" (pp.120), it cannot be judged what impact equity considerations have had on decisions, and therefore accountability and performance measurement cannot be undertaken.

One approach to establishing such trade-offs that is gaining prominence in the health economics literature is conjoint analysis (CA). The origins of its economic applications concern environment and transport issues. It is a technique that is used to estimate the relative weights that people attach to different attributes of commodities. It has been used extensively in health economics to value different components of health care relative to each other and has been applied particularly to the exploration of "process utilities" relative to health outcomes. Individuals are presented with hypothetical scenarios which are described by reference to a number of different attributes each of which are at different levels. A number of pairwise choices made between scenarios by

¹ As discussed in chapter four. See for example, Daniels (2000), Daniels and Sabin (1997, 1998).

sufficient numbers of respondents allows econometric estimation of the relative weights associated with different attributes, see for example Ryan (1998).

Whilst the approach has been applied predominantly to explore patient preferences, as opposed to citizen preferences, CA probably represents the most suitable tool for establishing trade-offs between health outcomes and non-consequential considerations. Yet it is my feeling that the technique is not sufficiently well developed to make such a project desirable at this moment in time and that, due to the nature of the components of a normatively acceptable pluralistic framework, the trade-off approach may not be desirable at all. If rights, duties, procedures and causes are deemed to be claim types that are incommensurable with outcomes based claims then the trade-off approach is flawed². The second of these points is discussed in more detail below (6.2.4) but on the practical issue of using CA to operationalise pluralism, there are three relevant points to note.

Firstly, the attributes that require inclusion in a conjoint analysis experiment attempting to establish the precise weights that should be allocated to competing claims in a pluralistic framework are not easily specified for such purposes. To take the procedural characteristics of reversibility and voice as illustrative examples, the experiment must be set up in such a way that these characteristics are clearly and unambiguously defined for respondents and, perhaps more difficult, meaningful levels applied to these attributes. It is unlikely that simple binary levels would be sufficient (the public were or were not consulted, challenges to the decision were or were not available), although this would be an obvious starting point were such an approach attempted. However, specifying multiple levels for such attributes (for example, high, medium, low) is likely

² This issue is discussed in more detail in Chapter three.

to result in categories that are highly ambiguous. This is a similar interpretation problem that exists in CAs that have examined process utility issues at the patient level. Ryan (1999) for example specifies “bad” and “good” as levels for “attitudes of staff” in an analysis of patient preferences for IVF treatment.

Secondly, the interpretation of results may be substantially contaminated by the inability to factor out instrumental values attached to non-consequential attributes of alternative rationing approaches, as opposed to the inherent values that can then be quantified as trade-offs with concerns for outcomes.

Thirdly, the methodology is still in its infancy and the reliability of study results in areas that appear more suitable to such experiments can appear counter intuitive. In Ryan’s (1999) IVF example, results indicate that individuals are willing to trade a 6% chance of successfully having a child for good staff attitudes despite the fact that the best possible chance of having a child was just 35%. Other evidence indicates that respondents find the cognitive burden of assessing scenarios defined according to several attributes too high and make their choices by reverting to simple heuristic devices, such as focussing solely on one or two attributes³.

6.2.2 The Capability Approach

Sen’s theory of capability rights is the only approach currently discussed by economists which emphasis the importance of both consequential and non-consequential considerations. Its potential relevance to the empirical evidence of previous chapters has been mentioned in chapter five but this is an appropriate point at which to discuss these links in more detail. A number of empirical applications of the capability approach have

³ A number of methodological issues are discussed in Ryan and Farrar (2000).

been undertaken and met with some success in policy making terms⁴. Whilst none has addressed the specific issue of health care rationing and whilst the capability approach may not be applicable wholesale, these studies indicate at least that some facets of that approach can be operationalised. Furthermore, if the feasibility and/or desirability of an approach that identifies trade-offs between different health-care claims is doubted, then Sen's work provides a useful potential alternative.

The following proposition highlights the components of a capability rights approach to health-care rationing and is intended only as a sketch. It builds on ideas found in Anand and Wailoo (2000) (pp.568). Health-care may be thought of as the *commodity* in this framework. It embodies certain characteristics which allow basic functionings, most obvious of which is health, which in turn allow us to perform more complex functionings, for example to be mobile. QALYs can be thought of as a proxy measure for these more complex functionings. This is closely related to the standard text-book definition of derived demand for health-care. In conceptualising this idea it is useful to start from a position where each individual claims equal entitlements to commodities. This is not only useful in relating the capability approach to the health-care rationing issue but has more of a descriptive relevance to the way in which this issue is commonly debated. Personal conversion factors which influence the translation of health-care into functionings are items such as physical characteristics, education, age and metabolism. Social conversion factors influencing the same relationship cover a wide range of non-consequential characteristics, for example, the procedural characteristics of decision making, discriminatory practices, attitudes to rights and perceived social contracts. Each of these impact on an individual's ability to convert initial equal entitlements into functionings and it is at this stage that much non-consequential information enters the

⁴ See Robeyns (2000) for a review of these applications.

assessment. The translation of functionings into capabilities however is determined by choice and perhaps the most relevant component here is the relevance of cause. For example, an individual's decision to smoke determines the achieved health functioning but not the capability to achieve better health. To concentrate on achieved functionings, or proxies such as QALYs, when alternative functioning sets could have been "chosen" misses vital information from the assessment.

The strengths of empirical applications of the capability approach has largely been related to the issues that have been included in the analysis as opposed to the methods by which these issues have been synthesised. These studies are largely descriptive, Robeyns (2000). For example, Sen's own attempt at illustrating the capability approach in the context of living standards in developing countries, Sen (1985), showed that measures of life expectancy, infant mortality, basic education and tertiary education, often contradicted measures of GNP per capita and that therefore differences in public policy *inter alia*, had huge impacts on capabilities such as survival and education. Similarly, the series of indices generated by the United Nations Human Development Reports are relatively crude in their synthesising of functionings.

6.2.3 A Positive Approach

Non-consequentialist concerns *can* enter formal analyses in much the same way as concerns for distributive equity do currently; separately to concerns for efficiency. As Sassi *et al.* (2001) report, economists such as Kaldor (1939), have argued that economics should make recommendations based on efficiency and leave decision-makers to make decisions based on distributive equity. Here, I am arguing that welfare is a function of efficiency, distributive equity and a set of non-consequential concerns

and that economists do not currently have the means of making assessments which combine all three of these dimensions. Reporting additional information alongside assessments of efficiency implies that decision-makers will be charged with making their own subjective assessments of the strengths of the trade-offs between dimensions. Some of the non-consequential information that is relevant in rationing decisions does not necessarily operate at the same level as cost-effectiveness information. For example, with respect to procedural issues such as transparency or the role of vested interests, non consequential concerns have clear implications for the design of institutions such as NICE in the UK. This does not imply that the implementation of these claims are costless, but it does allow the development of a framework of rules within which cost-effectiveness analysis (and other types of claims) can then be assessed.

6.3 RECOMMENDATIONS FOR FUTURE RESEARCH

One of the main implications of the findings of this thesis is that non-consequential information is a legitimate concern for economists but that our empirical and analytical understanding of these different concerns is still limited. Notwithstanding the possible future need for the quantification of trade-offs between alternative claims, there are several additional research issues to be developed prior to, or in place of, such work.

Firstly, whilst the evidence presented here has provided reasons for individuals to rationally value non consequentialist information, there is substantial scope for qualitative investigation of this issue. This approach would allow individuals (or groups of individuals) to explain their responses and shed further light on the extent to which inherent versus instrumental values underlie these apparent non consequentialist attitudes. Additionally, several of the procedural characteristics presented in this thesis

need not be assessed as either "on" or "off" in different decision making mechanisms. Rather, there is a range of possibilities. For example, vested interests may be entirely excluded from decision making, they may be used as an informational source only, or a range of alternative ways of including these views but controlling for any potential bias may be implemented⁵. Each of these alternatives will be more or less acceptable to individuals. The need to identify "good" procedures is a crucial element for any implementation method and also a requirement for techniques such as conjoint analysis, where respondents require "levels" of different characteristics to be defined.

Secondly, as has been stressed throughout this thesis, health care rationing is just one example of a substantive social choice problem. The findings in relation to pluralism require empirical investigation to establish whether this approach can be applied to other issues, or if the peculiarities of the health sector (or the health sector in the UK) have prompted these results. Replication of the methods used here, including the little used content analysis methods, can be employed to examine a range of both public and private sector decision making scenarios.

⁵ There is also a range of ways of defining what constitutes a vested interest.

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